

ELPA

European Liver
Patients' Association

Annual Report 2019

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ACRONYMS

ACHIEVE - Associations Collaborating on Hepatitis to Immunise and Eliminate the Viruses in Europe

AASLD - American Association for the Study of Liver Diseases

ACLF - Acute-on-Chronic Liver Failure

CEHC - Central European Hepatologic Collaboration

CHB - Chronic Hepatitis B

CSF - Civil Society Forum

DG - Directorate General

EASL - European Association for the Study of the Liver

ECDC - European Centre for Disease Prevention and Control

EF Clif - European Foundation for the study of chronic liver failure

EIT - European Institute for Innovation and Technology

EMA - European Medicine Agency

EMCDDA - European Monitoring Centre for Drugs and Drug Addiction

EPF - European Patients' Forum

ESCMID - European Society of Clinical Microbiology and Infectious Diseases

EU - European Union

EURODIS - Rare Diseases Europe

HBV - Hepatitis B Virus

HCV - Hepatitis C Virus

HE - Hepatic Encephalopathy

HEP - Hepatitis

HTAI - Health Technology Assessment International

ILC - International Liver Congress

NAFLD - Non-Alcoholic Fatty Liver Disease

NASH - Non-Alcoholic Steatohepatitis

NGO - Non Governmental Organization

PCWP - Patients' and Consumers' Working Party

PWID - People Who Inject Drugs

SLTC - Screening and Linkage to Care

TAG - Technical Advisory Group

TB - Tuberculosis

UNAIDS, - United Nations Programme on HIV/AIDS

VHPB - Viral Hepatitis Prevention Board

WHO - World Health Organisation

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Our Mission

ELPA emerged from a desire amongst European liver patient groups to share their experiences of the often very different approaches adopted in different countries. In June 2004, 13 patient groups from 10 European and Mediterranean basin countries met to create the association. ELPA was formally launched in Paris on April 10th 2005 during the annual conference of the European Association for the Study of the Liver (EASL) and now has 31 members from 25 countries.

ELPA's aim is to promote the interests of people with liver disease and in particular: to highlight the size of the problem, to promote awareness

and prevention, to address the low profile of liver disease as compared to other areas of medicine such as heart disease and to share experience of successful initiatives. ELPA and its members are dedicated to multi-level lobbying initiatives involving European Union and national policymakers, liver specialists, associations and public health experts. ELPA's vision is that all liver patients are diagnosed in time, treated with respect, and have equal access to the best standard of medical care – regardless of origin, lifestyle, and type of liver disease. Our ultimate goal is a world without liver diseases.

ELPA Values



Equality



Respect for
diversity



Patient
driven



Commitment



Transparency



Foreword of the President

Dear Stakeholders,

For 15 years now ELPA has been advocating to change the life of liver patients for the better and make their voices loudly heard. It has been a long and difficult journey but ELPA has never given up, being aware of the fact that what is at stake is saving lives.

If I take a look at the past I could describe many projects and events ELPA organized, and this overview of our activities throughout the 2019 is the proof of ELPA's efforts to push patients' needs on top of the scientific and political agenda. For this effort I thank all the ELPA members, ELPA governing board, ELPA scientific committee, ELPA supervisory board and our ELPA Brussels team. We had generous support from our business partners from pharma companies and also enormous support from the medical community. In the 2019 we managed to have a voice in every drug and medical device that is used in Europe and approved by European Medicine Agency and we also successfully engaged with more than 50 high level medical researchers and top institutions in supporting the medical research projects that will change the landscape of the liver patients care in Europe and beyond. European patients landscape is also changing with the appointment of the new Commissioner for health and several activities have been done to achieve better care for patients in Europe. ELPA is monitoring closely every health event in Europe also with help of most important information provider that was our close partner in 2019 the news company Politico.

Management of the association in the year 2019 was not easy as we needed to show all the stakeholders that ELPA is even stronger and bigger than the year before - with several new members we accepted at our annual general meeting. We managed not only to re-establish communication with all our stakeholders, but also to find new supporters and institutions that we want to work with in 2020 and beyond. Our team has several ideas and projects that will be done in the near future to establish higher quality management processes in the association.

We are immensely proud of the work that ELPA has done so far, and I believe that it should inspire you to support our work and to comprehend the importance of an association like ELPA.

However, much more should be done in the future to put patients increasingly in the spotlight. For that reason, ELPA will be continuing to fight to assure that all liver patients are diagnosed in time, treated with respect and have equal access to the best standard of medical care because our ultimate goal is a world without liver diseases.

Marko Korenjak, President of the European Liver Patients' Association (ELPA)



ELPA Members in 2019



BELGIUM

- Vlaams Hepatitis Contactpunt - VHC



BOSNIA & HERZEGOVINA

- The Chronic Viral Hepatitis Patients Association, "B18"



CROATIA

- Croatian association for liver diseases, "Hepatos"



CYPRUS

- Cyprus Liver Patients Association, "Promitheas"



DENMARK

- Leverforeningen



EGYPT

- Association of Liver Patients' Care – ALPC



FINLAND

- The Finnish Kidney and Liver Association



FRANCE

- SOS Hépatites Fédération



GEORGIA

- Hepatitis C Cured Patient Association



HUNGARY

- Hungarian Association of Chronic Hepatitis Patients, "VIMOR"



IRELAND

- Hepatitis C Partnership



ISRAEL

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



MACEDONIA

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



NORWAY

- proLAR



POLAND

- Star of Hope Foundation



PORTUGAL

- SOS Hépatites Portugal



ROMANIA

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



RUSSIA

- Humanitarian Action,
- United Against Hepatitis



SERBIA

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



SLOVAKIA

- HEP HELP KLUB,
- Šanca pre pečeň



SLOVENIA

- Slovenian Association for patients with viral hepatitis - Slovenia HEP



SPAIN

- Catalan Association of Hepatitis Patients - ASSCAT,
- National Federation of Liver Patients and Transplanted - FNETH



SWEDEN

- Riksföreningen Hepatit C – RHC



TURKEY

- Living with Hepatitis Association - HEPYAŞAM



UNITED KINGDOM

- British Liver Trust,
- Hep C Positive,
- Liver4Life



2019

Highlights

Annual General Meeting

The AGM in Vienna took place on 18th April 2019 and it was a successful opportunity to exchange ideas and opinions. Indeed, ELPA members had the possibility to present to others their commitment at the national level along with their activities and the best practices they put in place.

ELPA Pre-Summit on NAFLD

PATIENT'S PERSPECTIVE MEETING

Pre-Summit was held on 26th September 2019 in Seville, Spain. The fatty liver problem will be one of the biggest issues in Europe in the next decade.

ELPA is very happy that also doctors are recognizing the importance of patient' Pre-Summit events, such as this one. ELPA Pre-Summit on NAFLD successfully reached the objectives – to highlight the importance of patient as a center of the treatment, to have a scientific discussion on NAFLD and NASH with well-known speakers and most of all to hear the experience from patients themselves.

The event has been organized by the ELPA Scientific Committee leader, Dr. Teresa Casanovas Taltavull. ELPA Pre-Summit has been moderated by Prof. Gamal Shiha and Dr. Salvador Augustin. Prof. Manuel Romero Gomez presented the NAFLD overview and the impact of the correct diagnosis and management. Prof. Elena Maestre gave a very interesting presentation with practical guidance regarding good nutrition and lifestyle. Prof. Helena Cortez-Pinto spoke more about NAFLD, Public Health and education strategies in Europe. ELPA has had a privilege to hear patients' personal experience of bariatric surgery and life with the transplanted liver. Dr. Maria Mercadal gave an overview of solving childhood obesity and NAFLD and also she presented some of the projects in Europe focused on childhood obesity.

ELPA is part of PCWP at EMA

For several years ELPA was part of eligible organizations to offer support, advice and participation at the consultations in European Medicine Agency. From this year, we are also part of The Patients' and Consumers' Working Party at European Medicine Agency. The Patients' and Consumers' Working Party (PCWP) provides a platform for exchange of information and discussion of issues of common interest between EMA and patients and consumers. The PCWP, established in 2006, has enabled the Agency to build upon its existing interactions with patients and consumers. It provides recommendations to EMA and its human scientific committees on all matters of interest in relation to medicines.

ELPA activities during EASL ILC 2019, ELPA's President opening speech

EASL International Liver conference 2019 in Vienna was again attended by over 10.000 medical experts, researchers and patients. ELPA had one booth used mainly for meetings and to represent the association and we had another booth slot which has been used for a screening van, equipped with FibroScan where attendees were able to check their liver status and learn all about screening activities that have been going on within. ELPA board had an opportunity to meet before EASL ILC where members discussed future steps in order for ELPA to grow bigger and become stronger. ELPA members had the opportunity to attend the most prominent lectures from experts all over the world.

ELPA Symposium, ILC 2019

ELPA Symposium was attended by more than 1.000 people which was an enormous success. With ELPA

Symposium, we tried to bring more attention to the problems that liver patients are facing in the field of NAFLD and NASH and we can say that we succeed by bringing experts with key topics such as diagnosis of NASH/NAFLD, the importance of right nutrition, clear information, the role of Transient elastography.

Visits to the Hospital Clinic in Barcelona

HEPATOLOGY UNIT

During the ELPA educational training in Barcelona ELPA was also honored to have secured a visit for all ELPA members at the Hospital Clinic in Barcelona – Hepatology unit. We had this opportunity thanks to the leader of our Scientific Committee Ms. Teresa Casanovas. This liver unit is the biggest liver unit in Europe and one of the biggest in the world. The visit took place on 3rd December in the afternoon and the tour was followed by presentations by Prof. Dr. Pere Ginès, Prof. Isabelle Graupera and nurses Ms. Nuria Fabrellas, and Ms. Marta Cervera. They gave us an overview of the contents of LiverScreen and LiverHope projects from their professional perspective and stressed the importance of nurses' work in treating patients with non-alcoholic fatty liver in primary care.

ELPA and its President Marko Korenjak also awarded Prof. Dr. Ginès with a certificate of appreciation for his work with us in the project LiverScreen funded by European Institute for Innovation and Tehnology in 2018 regarding the tireless and constant support of liver patients.

ELPA Partnership with POLITICO

ELPA subscribed a partnership with POLITICO, one of the most famous pan-European newspaper, regarding the access to all the health events and





news in Europe and beyond. In June 2018, an annual ComRes/Burson-Marsteller survey ranked POLITICO as the #1 most influential publication on European affairs, for the second year running.

NAFLD – NASH meeting in European Commission

“Preventing NAFLD-NASH epidemic in EU – patients’ perspective” meeting was held on 8th of January in European Commission, Brussels. The meeting was hosted by Carlos Moedas, European Commissioner for Science, Research and Innovation, who delivered a key-note speech. The meeting was chaired by ELPA President, Marko Korenjak and has gathered following speakers: Prof. Dr. Rajiv Jalan, Prof. Jeffrey Lazarus, Prof. Dr. Helena Cortez Pinto, Prof. Dr. Quentin M. Anstee, Prof. Dr. Manuel Romero-Gómez, Dr. Jörn M. Schattenberg and Elena Balestra.

That was a second ELPA’s meeting covering NAFLD-NASH topic on EU policy level and the plan for the third edition have already started.

The launch of the White paper on HE meeting

ELPA, as part of its Time To Deliver Campaign, in order to raise awareness on Hepatic Encephalopathy produced a White Paper on HE. The launch of the White Paper on “The Burden of Liver Disease in Europe” was held on the 26th February in the European Parliament, Brussels. The meeting started with a welcome from MEP Cristian Silvio Bosoi, who spoke on concrete EU and national level policy actions required to secure better futures for patients. ELPA’s Interim CEO Lana Crnjac presented the White paper. Marko Korenjak, ELPA’s President stressed the importance of raising awareness of the burden of Hepatic Encephalopathy (HE), a serious complication of advanced chronic liver disease. Frédéric Destrebecq, Executive Director of the European Brain Council outlined the policy actions required by National Governments to secure a better future for people with HE.





The image features a monochromatic orange background. In the foreground, the silhouettes of three individuals are shown in profile, facing right. They are overlaid with a white network diagram consisting of circular nodes connected by thin lines. The background shows a city skyline with various skyscrapers. The text 'Policy and Advocacy Work' is centered in the lower half of the image.

Policy and **Advocacy Work**

WHO meeting in Georgia

World Health Organization Regional Office for Europe organized the First Regional Consultation on Viral Hepatitis in the WHO European Region: Progress on the Way to Elimination, Tbilisi from 11th till 13th February 2019. The purpose of the consultation was to review countries' progress in implementing the Action Plan for the Health Sector Response to Viral Hepatitis in the WHO European Region and to exchange good practices in viral hepatitis response and monitoring. Meeting, which was attended by the representatives from 45 different countries and 30 international organization from all Member States of the WHO European Region, had the aim of bringing together senior officials responsible for communicable disease programmes and national viral hepatitis programme managers, as well as representatives of key partner institutions, professional associations, civil society and medical humanitarian organizations, WHO collaborating centers and donors. ELPA was represented by ELPA President Marko Korenjak, who co-chaired part of the meeting connected to reporting on national planning where several countries presented their national activities towards viral hepatitis elimination and ELPA Board member, Tatjana Reic, who has also participated as representative of ACHIEVE coalition. She has, during the panel discussion titled "The role of partnerships for hepatitis response in the WHO European region", presented the work of ACHIEVE coalition and ELPA's involvement with different stakeholders, especially in regards to working in different research medical projects like LIVE HOPE, LIVE SCREEN.

7th Scientific International Conference

ALL ABOUT PEOPLE: FUTURE FIT!

The 7th scientific conference was held on 15th and 16th March 2019 in Maribor, Slovenia, with an emphasis on sections and round tables. There were representatives from 20 different countries and

overall more than 1,000 participants. The section on Health and health services in light of sustainable development was dedicated to the questions of public health. ELPA was represented by the President Marko Korenjak, who had an opportunity to present ELPA's involvement in scientific projects LiverHope, Micro-Predict Horizont 2020 and LiverScreen.

EuroTEST/European Testing Week & INTEGRATE

NATIONAL STAKEHOLDERS MEETING AND TRAINING

The meeting was held on 10th April 2019, 13.00-20.00h at Croatian Institute of Public Health, Zagreb, Croatia. The discussion was about Spring Testing Week, November Testing Week, financial overview, monitoring, and evaluation of the testing weeks. The main aim of the meeting was to bring together regional, national and local stakeholders to discuss current testing strategies for HIV, viral hepatitis and sexually transmitted infections.

VHPB Advisory meeting and Technical meeting

"THE IMPACT OF VIRAL HEPATITIS TREATMENT AND VACCINATION NON-RESPONDERS AND OCCULT HEPATITIS ON PUBLIC HEALTH"

Meetings were held on 25th and 26th of April in Vilnius, Lithuania. During the Technical meeting entitled "The impact of viral hepatitis treatment and vaccination non-responders and occult hepatitis on public health" global scientists, opinion leaders, hepatologists, vaccinologists, pediatricians, and public health representatives who are experts in the field of viral hepatitis treatment and prevention, representatives of viral hepatitis or health organizations involved in the prevention and control of viral hepatitis and VHPB advisors

met together with the objectives: Hepatitis C Treatment hurdles non-responders - reinfection - relapse, Hepatitis B Vaccine Non-responders, Occult Hepatitis B. The last day of the meetings Ms. Tatjana Reic together with Johannes Hallauer chaired Session 4 (last session of the meeting) which summarized the Meeting Conclusion.

Launch of Romanian Strategic Plan

TO ELIMINATE VIRAL HEPATITIS 2018-2030

On 14th May in Bucharest, Romania, Romanian Ministry of Health in partnership with ELPA and ELPA member APAH-RO, launched Romanian Strategic Plan to Eliminate Viral Hepatitis 2018-2030. At the moment, Romania is the 18th country who has an official plan to eliminate viral hepatitis according to WHO recommendation. Romanian Ministry of Health stated that the purpose of the National Framework Plan is to minimize the extent of viral hepatitis as a public health issue by reducing transmission of hepatitis viruses, reducing morbidity and mortality by viral hepatitis and their complications, and by ensuring fair access to comprehensive prevention, testing, care, and treatment. The Ministry of Health and Romanian association APAH-RO under the leadership of Ms. Marinela Debu and ELPA have together presented The National Framework Plan to Control Viral Hepatitis in Romania for the period from 2019 to 2030.

Round Table

1ST CROATIAN SCIENTIFIC EVENT WITH POLITICAL GOAL

Expert meeting titled "Focus on Silent Liver Epidemics: Viral Hepatitis and Fat Liver" was held in Zagreb on 21st and 22nd May, organized by the Croatian Society for Liver Disease "Hepatos".

For two days, the meeting brought together eminent speakers and prominent international guests, such as Massimo Colombo, EASL International Foundation for Liver Disease, Dr. Antons Mozalevskis, a representative of the World Health Organization, numerous representatives of the European Association of Patients with Liver Diseases (ELPA), the Committee on (VHPB), as well as guests from the wider region (Slovenia, Bosnia and Herzegovina, Montenegro, Serbia, Macedonia, Kosovo, Albania) and local experts closely related to the area of hepatic healing.

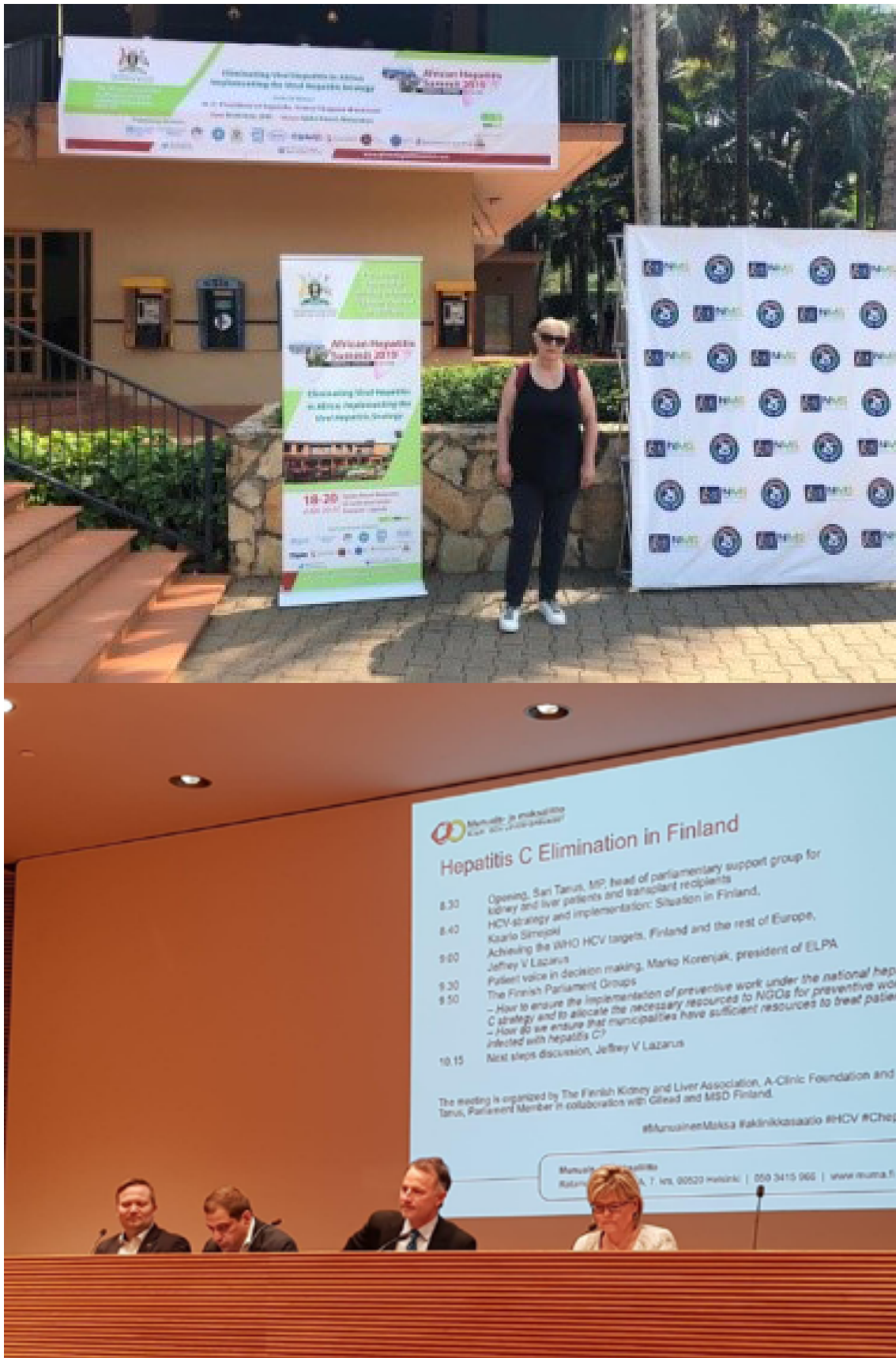
Symposium "System Medicine in Clinical Practice"

The International meeting on system medicine was held in Ljubljana, Slovenia on 10th June 2019. Our representative on this meeting, Marko Korenjak, talked about patient perspective in the system of medicine. A future of different levels of care in health care systems (in order to increase involvement of patients) and the impact of system medicine in specific disease case, were some of the topics at the meeting.

International NASH day conference

ELPA Vice-President, Julio Burman and ELPA President, Marko Korenjak participated at International NASH day conference on 12th June in Brussels, Belgium. The main discussion was about questions: Can we transfer a good practice from Hepatitis field to NAFLD and NASH and what are the challenges for health authorities and medical professionals?





Viral hepatitis and Tuberculosis Civil Society forum

EU HIV/AIDS

During the first day session which took place on June 17th in Luxemburg, CSF members have received an update from the European Commission and from the Agencies (WHO, UNAIDS, ECDC, EMCDDA). A debriefing from various policy events and processes that forum members participated at was received. During the “Key developments at the country/key population level and key policy developments” session ELPA representative, Tatjana Reic, has been given the opportunity to present changes in ELPA and update the forum on ACHIEVE’s activities. At the morning session on the second day ELPA representative participated in the continuation of CSF meeting during which present and upcoming EU Presidencies: Finland, Croatia, Germany, and Portugal were discussed. ELPA representative also participated at the session “Challenges in the funding of HIV/hep/TB response in Central and Eastern Europe: the role of EC and civil society in ensuring the sustainability of services”. ELPA was represented by Tatjana Reic.

Elimination of hepatitis-Finland

ELPA President, Marko Korenjak and ELPA Vice-President, Julio Burman were invited by our Finland member association to participate in the meeting “Elimination of hepatitis in Finland” in Finish Parliament on 13th June 2019. At the workshop which was organized by Finish association, ELPA’s work and future plans regarding the elimination of hepatitis were also presented to other NGOs that are interested in hepatitis elimination. After the meeting in Finish Parliament the meeting continued with NGO’s representatives. ELPA Vice-President Julio Burman had a presentation about the work of

ELPA in elimination of hepatitis with special focus on micro elimination.

African Hepatitis Summit 2019

“ELIMINATING VIRAL HEPATITIS IN AFRICA; IMPLEMENTING THE VIRAL HEPATITIS STRATEGY”

The first ever African Hepatitis summit was held in Kampala, Uganda from 20th -24th June.

AHS2019 brought together patient representatives, ministers of health, policymakers, civil society, international organizations, global funders and public health specialists under one roof to provide regional effects to tackle viral hepatitis. This event, themed “Eliminating Viral Hepatitis in Africa; Implementing the viral hepatitis strategy”, was designed to strengthen the broader hepatitis community by sharing ideas, experiences and best practice in addressing the many challenges of viral hepatitis in the region. During the meeting, both regional and international experts from WHO have had an opportunity to present and all participants were able to hear and share ideas for specific country case.

International HTAI meeting

The meeting was held in Cologne, Germany on 18th June. Marko Korenjak represented ELPA at the meeting. All participants were engaged in a large discussion about the work which has been done until now in the medical research project CoreNASH. CoreNASH was a project led by US, focused on the final point that clinical research in NASH must include. The panel discussion was led by PI of coreNASH and explored the work done by Delphi methodology in coreNASH and coreHEM. Numerous ways were explored on how to improve the engagement of the patients and patient advocates into research. It was concluded



that more data are needed on engaging patients into research.

The 5th Paris NASH Meeting

The meeting was held on 11th – 12th July 2019 in Paris, France. As in previous years, the meeting brought stakeholders from different backgrounds to present and discuss a series of topics that are likely to become highly relevant in the future but which are not yet in the spotlight in more traditional NASH meeting venues. Beside clinical aspects of NASH, the program included technological innovations, precision medicine and innovations in pharmacology and regulatory science. Working interactive sessions and abstract-driven programming were also provided. ELPA President opened the first session with opening speech and a presentation.

3rd meeting EASL

LANCET - COMMISSION ON LIVER DISEASE IN EUROPE

EASL-LANCET Commission meeting was held in Geneva 29-30 of August.

The goal of the Commission is to identify key challenges and opportunities for tackling the increasing health burden and the changing and diverse landscape of liver diseases in Europe.

Tatjana Reic participated as commissioner on behalf of ELPA in the work of viral hepatitis and stigma group. Tatjana Reic has also contributed to primary health care and education group on this meeting.

Meetings at the European Parliament

ABOUT THE IMPORTANCE OF LIVER AND LIVER DISEASES

After the election of the new European Parliament, we need to re-establish communication with the MEPs. Marko Korenjak visited EU Parliament in Brussels from 2nd to 4th of September where he held very important meetings.

Our first NASH/NAFLD summit was organized at the European Parliament after the MEP Mr. Peterle was able to host and co-chair the ELPA event and he was a great supporter of our activities. Unfortunately, he was not re-elected to the European Parliament, but Ms. Novak not only stepped into his shoes but increased her impact as a member of the ENVI committee in European Parliament. It is important for ELPA to establish good connections to the MEPs and Mrs. Novak was the first one after the new elected European Parliament. She is a great supporter of our activities and will help us to bring forward the topics that are important for liver patients in Europe.

ECDC meeting

ECDC meeting about the data in the hepatitis elimination program was held in Stockholm, Sweden from 16th -18th September.

ECDC presented work in HIV and data that was covered there as well as data that is collected in viral hepatitis and there were discussions on the document that is being prepared (will be finished until the end of the year) about viral hepatitis in Europe.

The participants at the meeting were specialists in epidemiology, persons from ECDC and representatives of patients organizations — Kerry James (WHA) and Nikos Dedes (as Civil Society Forum representative). ELPA's representative was Marko Korenjak who had a meeting at ECDC

headquarters with the main person for hepatitis communication; they discussed the ECDC and ELPA communication and made a plan to increase the cooperation in 2020 and beyond. He also had a meeting with ELPA member from Sweden in their office discussing work and position of ELPA in Sweden NGO's.

Cooperation between Norgine and ELPA

Several international companies strive to produce patient materials that would be beneficial for patients, patient advocates, family members, and care givers.

After the meeting with Norgine in Ljubljana and Split we decided to produce together with them, a series of patient materials that explain in simple and understandable language complex medical issues.

PCWP meetings at EMA

Meeting was held in Amsterdam, Nederland, 24th -25th September. They started with new elections for the PCWP co-chair in which ELPA representative Marko Korenjak participated. For ELPA this was a good opportunity as we got 3 to 5 minutes presentation time so now all PCWP members were introduced with our work. Kaisa Immonen has been the co-chair for the last three years and she was also re-elected. Later on, an overview was shown of the research that EPF is doing on patient participation in medical research and the process of including the patient in safety processes for different drugs. The patient's representative of EURODIS had a presentation and they shared a video overview of the work of PCWP in the last three years. After first day sessions, Marko Korenjak had a formal dinner with Prof. Krag where they discussed the activities in the projects Galaxy and II/microbe Predict and made future plans for ELPA's participation in medical research projects in Horizon 2020. The



second day meeting was held at the European Medicine Agency. The meeting was a joint meeting between the patients and the consumer party and healthcare professionals' party. The topics were mainly focused on the anti-vaccination movement presented by EMA and ECDC and the new web page that will tackle this issue, presentation of EPF research on patient participation, EMA presentation on pharmacovigilance and topics for next EMA meeting with the parties.

ESCMID meeting

ELPA participated at ESCMID postgraduate course on hepatitis elimination in Ljubljana on 28th September 2019. We were represented by Marko Korenjak who had a presentation on hepatitis elimination from a patient perspective. He also had meetings with Prof. Maticic from Slovenia



and Prof. Preveden from Serbia. They agreed that Serbia needs a continuation of ELPA's support because they still have extremely limited access to treatment. Screening van from Croatia association Hepatos was mentioned as an example of good practice and something Serbia needs, given the fact that Serbia has only one fibroscan.

9th CEHC conference

ELPA President Marko Korenjak participated at the 9th Conference of the Central European Hepatologic Collaboration (CEHC) in Warsaw on 11th October 2019. He presented the European Liver Patient Association, its commitment in different projects such as: LiverHope, Microb-Predict, FisPlat, LiverScreen, IP-cure-P, and Decision. He stressed that ELPA strongly encourages and supports the professional community in top research about

liver diseases in Europe. Moreover, he emphasized the fact that all the projects ELPA is involved in are patients-oriented and designed to increase the benefits for them.

6th Polish Academy of Contemporary Hepatology

At the 6th Polish Academy of Contemporary Hepatology held in Warsaw on 12th October 2019, ELPA president, Marko Korenjak outlined the state of the art on hepatitis elimination in Europe from the point of view of patient communities. He also presented some of the European best practices. Moreover, he described the different effort in hepatitis elimination in Poland comparing the current situation to that of 2017 taking into account that ELPA was there in Warsaw with the ELPA@Home project. Indeed, ELPA has been supportive to the patient communities and experts in their work towards WHO elimination goals. Especially we want to thank Barbara Pepke, who is the leader of ELPA's member from Poland, for her contribution until now to improve the situation for liver patients in her country. However Poland needs stronger steps forward to reach hepatitis elimination by 2030.

Screening and Linkage to Care (SLTC) conference

Screening and Linkage to Care (SLTC) conference was held in Valencia on 15th October. It was organized by Gilead and several of ELPA national members were invited to participate. On behalf of the European Liver Patient Association, ELPA President Marko Korenjak attended the conference. After the presentation of some of the European best practices, it was discussed what is the best way to improve the Linkage to Care in Europe and what the next steps should be. At the conference, the ELPA president conducted several meetings with different ELPA's members and also with Gilead as one of ELPA most important stakeholders.



EU Health Policy Platform

ELPA board member Milan Mishkovikj and ELPA President, Marko Korenjak participated at the event organized by the European Commission, DG Health, in Brussels on 17th October. The event was the opportunity to discuss different projects in the framework of the EU Horizon 2020 research program and talk about the upcoming years. The next program will be bigger than Horizon 2020 - from 75 billion EUR to 100 billion EUR and will include also a section on research in health. The NGOs that are part of the EU Health Policy Platform were invited to present their projects for the next calls. Concerning that, ELPA was invited to join the EU Health Policy Platform. In addition, during the event, the winners of the biggest contributions to the European society in the field of health were announced.

VHPB Adviser meeting and meeting

“ELIMINATION OF VIRAL HEPATITIS IN HUNGARY: LESSONS LEARNED AND THE WAY FORWARD”

The VHPB adviser meeting was held in Budapest on 29th October. ELPA's representative was Tatjana Reic. During the meeting, various topics were discussed such as the composition and structure of the Viral Hepatitis Prevention Board as well as planning future meetings. IN Budapest from 30th - 31st October, ELPA representative Tatjana Reic also participated at the meeting about “Elimination of Viral Hepatitis in Hungary: lessons learned and the way forward”. The meeting objectives were to provide an overview of the current viral hepatitis situation in Hungary, surveillance systems, epidemiology, screening, prevention and the cascade of care and the possible implementation of new prevention strategies in Hungary. The meeting was organized with the intended impact of putting prevention and control of viral hepatitis on the national public health agenda, discuss the current

situation and the way forward to contribute in fighting against hepatitis in Hungary and achieving the elimination of viral hepatitis as a major public health problem by 2030.

Monitoring of hepatitis B and C in the EU

The conference “Monitoring of hepatitis B and C in the EU”, was held at ECDC in Stockholm, Sweden on 11-12 November 2019. Marko Korenjak was invited as ELPA's representing. He presented ELPA's activities regarding the prevention of hepatitis B and C in Europe during the panel discussion “Addressing the data gaps”. This session was aimed at discussing how to address identified data gaps in the responses to hepatitis B and C.

AASLD meeting in Boston

From November 8th to November 12th, 2019 ELPA participated in the AASLD meeting in Boston. ELPA was represented by President Marko Korenjak, Vice-President Julio Burman and Dr.Teresa Casanovas Coordinator of the ELPA Scientific Committee.

The main purpose of the ELPA attendance at the congress was to connect and create an ever closer network with stakeholders and industry, seeking new opportunities and putting liver patients in the spotlight. Indeed, during these days, ELPA representatives participated in several meetings discussing future collaborations in the upcoming years and especially in 2020. The AASLD meeting has been a wonderful opportunity to deepen ELPA networking, share ideas, knowledge, and experiences, without forgetting how this participation has fostered the searching for new common objectives.

European Patients' Forum - EPF congress 2019

ELPA, represented by Milan Mishkovikj was part of the first-ever European Congress on patient involvement driven by leading representatives of the patient community, and patient experts, in Brussels on 12-14 November 2019. With 72 members, the European Patients' Forum represents the interests of an estimated 150 million people with chronic diseases and the congress was attended not only by high-level advisers from NGOs but also by governmental, academic and healthcare industry representatives. Gathering together was an amazing opportunity to stress why patient involvement is a strategic imperative for all health stakeholders and how we can progress on this more effectively across Europe and beyond.



Science Symposium and 5th TAG meeting

OF GEORGIAN GOVERNMENT'S HEPATITIS C ELIMINATION PROGRAM

Meetings were held from 18th- 20th November, in Tbilisi, Georgia. ELPA was represented by Tatjana Reic, the TAG member. Technical Advisory Group actively participated in giving recommendations to the Georgian government in regard to Advocacy, Awareness, Education, and Partnerships for HCV-Associated Resource Mobilization.



HCV – Screening and Linkage to Care Conference

The conference titled "HCV – Screening, and Linkage to Care" was held in Bled, Slovenia on 30th November 2019. ELPA's representative was President Marko Korenjak also representing the Slovenian association. He was with Milan Mishkovikj from the Macedonian Association, Tatjana Reic







from the Croatian association and Ivana Dragojevic from the Serbian one. During the panel discussion “HCV Elimination Perspectives”, ELPA’s president presented ELPA’s activities regarding hepatitis elimination in Europe. He also participated as a presenter to the panel discussion “HCV Elimination: Patients in Focus”. During this session, he gave an overview of liver patients’ perspectives in Europe starting from his own personal experience as a patient.

“Give a happy end to hepatitis” meeting

During diagnosis week campaign ELPA President of the Scientific Committee Teresa Casanovas participated in a session where a famous Spanish actor Carmelo Gomez gave a presentation about his experience having Hep C. The doctor who was treating him also participated in the presentation. The meeting was held in Barcelona, Spain on 2nd December.

Having no visible symptoms he had been living his life without knowing that he is HCV positive until he donated blood. He presented his story from diagnosing to the cure. He and his doctor played as a team from the beginning. Both of them at the end stressed the importance of early diagnosis, testing, and decrease of the stigma towards patients with hepatitis C.

Carmelo Gomez: “When I thought that all was lost the new pills appeared, the solution without fever,


no adverse events, all-oral, and in a few weeks I was cured. This is why is crucial to be tested, so get tested for hep C and make the history of hep C have a happy ending”, was the conclusion of the meeting.

ACHIEVE meeting

“Collaborating on Hepatitis to Immunise and Eliminate the Viruses in Europe” meeting was held in Brussels on 12th December. They presented what has been done in 2019 and what is going to be done this year. Coalition’s focus for this year is to ensure at the highest levels that the EU Commission and Parliament’s agendas include hepatitis as an important topic. The current chair of the Coalition Tatjana Reić, ELPA Board member, announced that she would step down the next year.

NASH patient expert meeting

The meeting was held in Berlin on 17th December. ELPA was represented by Marko Korenjak. Some of the discussed topics were: lack of information, not enough research/trials, and difficulties to diagnose patients. As a conclusion from our President, it will be useful for ELPA to establish an ELPA led working group on NAFLD/NASH.

A photograph of several hands of different skin tones stacked together in a circle, symbolizing unity, teamwork, and support. The image is overlaid with a semi-transparent orange filter. The text "Empowering our Members" is written in white, bold, sans-serif font in the lower-left quadrant.

Empowering our Members

ELPA@Home, Poland

Poland was one of the first countries that ELPA visited when the ELPA@Home project started. Now in 2019, we visited Warsaw once again from 22nd – 23rd September for the continuation of our work.

As always the first day started with a workshop for different NGOs where they had an opportunity to present the work their organizations have had and the problems with hepatitis elimination in Poland until now. In the afternoon sessions, Julio Burman and Marko Korenjak presented a plan about the hepatitis elimination in Europe and how to set up a new action plan for Poland. Day one finished with conversations about the most important topics which need to be raised at a press conference the day after.

ELPA@Home, Romania

Between March 27th – 29th, 2019, representatives of ELPA, Julio Burman and Ivana Dragojević were present in Romania at the invitation of the Romanian Liver Patients Association (APAH-RO). The main objectives of this visit included strengthening the activities aimed at eliminating viral hepatitis in Romania and promoting the ELPA@Home initiative which focuses on a multi-sectoral approach when dealing with viral hepatitis. During our visit we had the great chance and honor to meet representatives of the Ministry of Education, Bucharest School Inspectorate, where we presented ELPA@Home Romania/pilot project “Protect yourself With Knowledge”, building a preventive package of services and education for adolescents on the topic of viral hepatitis (to include education in the education system). Romanian National Society of Family Medicine, WHO Romania, Public Health Department from the Presidential Administration, NGOs, the medical community, where we presented ELPA@Home PWID and Fatty liver programme.

ELPA@Home, Istanbul

Our member from Turkey, Hep-Yasam, invited ELPA to visit Istanbul with the ELPA@Home project from June 24th - 25th. On the first day project leader and ELPA Vice-President, Julio Burman held a workshop for various NGOs that are interested in the elimination of hepatitis. On the second day, a meeting was held with all stakeholders including representatives of the Ministry of Health and the Ministry of Finance. ELPA Vice-President Ivana Dragojević presented ELPA’s work so far, and in particular the ELPA@Home project. The program for this visit was based on the data collected in the HepCore study and it was based on the guidelines and recommendations we received from our member Hep-Yasam. As a conclusion of two-day meetings, a declaration was signed on the cooperation of all stakeholders on the elimination of hepatitis in Turkey.

#EndHep Europe initiative

On World Hepatitis Day on 28th July, ELPA launched #EndHep Europe initiative to stress the importance of keep on fighting for Europe without hepatitis.

We encouraged our members to join ELPA’s biggest social media initiative on hepatitis elimination in Europe, to help us spread the voice of #EndHep in Europe on #worldhepatitisday2019.

ELPA also offered EndHep campaign materials to be used on World hepatitis day.

ELPA’s visit to Norway

The purpose of the trip was to support ELPA member NGO ProLAR that conducted national conference on hepatitis elimination and harm reduction services.

The program incorporated also new ELPA project for harm reduction Music4Life executed by ELPA

member from UK under leadership of Phil Spalding. The program Music4Life presented several ways to use music for health education of most vulnerable and neglected people in the society.

There is a strong international movement to end the stigmatization of liver patients in Europe. In Norway, the movement is led by Patrik Karlsen. ELPA president Marko Korenjak together with Patrick Karlsen sent a strong message on social media expressing the commitment to support activities to end the stigmatization of liver patients in Europe.

The vision of the liver patients in the European environment

On 24th October in Madrid FNETH celebrated its 15th anniversary. They organized educational sessions for their members in Madrid where ELPA was invited.

Our representative was Teresa Casanovas. She presented on "The vision of the liver patient in Europe" and talked about the role of ELPA and its objectives related to liver patients.







Strengthening
our association

ELPA Educational Days

SPLIT, CROATIA

ELPA Educational Days were held in Split, Croatia, where 22 ELPA members' representatives came together from 26th to 27th June 2019 to exchange opinions, follow up on ELPA's work and progress and create a clear vision for the future. The first day was proposed by company Norgine, when we talked about the importance of social media activities of ELPA members. ELPA members received valuable information and exact steps on how to create their social media image, how to operate their profile and how to communicate in order to reach every part of Europe with their dissemination activities. As per systematically organized agenda, the meeting was very easy to follow despite the complexity of the subject. The program was set up by a world-class company that works in social media and we are happy that Norgine covered all educational fees, transfer costs and accommodation of the lecturers. The second day was focused on the first step to crafting the new ELPA strategy plan for the period 2020 – 2023. This is such an important step which needed to be done with all ELPA members. The meeting was very successful and fruitful with numerous innovative ideas on how to make ELPA even better and how to proceed forward.

Stakeholders' meeting and ELPA educational training

BARCELONA, SPAIN

Stakeholders' meeting and ELPA educational training were held from 2nd to 5th December in Barcelona, Spain. We started with the Stakeholders' meeting and it was an incredible opportunity to exchange views identifying our future common objectives. ELPA Team provided ELPA members with an overview of ELPA's past and future activities. In the afternoon on 2nd December, an ELPA Extraordinary General meeting was held. This meeting was the occasion to gather together, reflecting on our association and pushing forward our work. A new ELPA's Statute was adopted.

On 3rd and 4th December, ELPA educational training program took place where ELPA members had the possibility to hear speakers presenting some inspiring projects and to debate amongst them and companies. During the last day, on 5th December, a round table was set up. We discussed how to improve NASH care in Europe from the perspective of liver patients.







ELPA in
**research
projects**

In 2019 ELPA was already involved in the following medical research projects Horizon 2020: Galaxy, Liverhope and Microb-Predict. During the entire year ELPA participated in preparing several medical research project proposals. ELPA is proud to announce that, since the beginning of 2020, it has been also participating in three more medical research projects Horizon 2020: Liverscreen, IP-cure-B and Decision and in the Medical research project FiSplat, European Institute for Innovation and Tehnology – EIT Health, for a total of seven medical research projects.



Medical research project Galaxy, Horizon 2020

Medical research project GALAXY brings together partners with unique research competences in clinical hepatology, microbiome, multi-omics, biomarkers and bioinformatics. The aim of the project partners is to develop novel systems medicine tools which integrate clinical, multi-omics and lifestyle information from alcohol over-users at various stages of the disease and healthy individuals in order to: 1) identify signatures of host-microbial cross-talk during disease development and progression, 2) translate this into biomarkers for diagnosis, stratification and treatment monitoring in alcohol over users, and 3) evaluate new interventions to modulate gut microbiota towards prevention and mitigation of the disease in at-risk individuals. Project partners will also study societal and economic impact of medical research project GALAXY biomarkers and treatments to accelerate future development.



Medical research project Liverhope, Horizon 2020

The objective of Liverhope is to evaluate a novel therapeutic strategy for patients with decompensated cirrhosis based on targeting the main pathophysiological mechanisms of disease progression in cirrhosis, namely the impairment in the gut-liver axis and the persistent hepatic and systemic inflammatory response.

This dual therapeutic approach is supported by preclinical data showing that rifaximin modulates the disturbed microbiota and decreases gut permeability and systemic endotoxin levels characteristics of cirrhosis. Moreover, simvastatin decreases systemic and hepatic inflammation, improves the altered hepatic microcirculation, decreases portal hypertension, and reduces fibrosis progression.







Medical research project Microb-Predict, Horizon 2020

Within medical research project Microb-Predict, project partners are investigating the human microbiome to identify predictors and mechanisms associated with the development of decompensation of cirrhosis and progression to acute-on-chronic liver failure (ACLF) and death. The project gathers 22 partner organizations working in different fields.

8 European countries are collaborating and performing research in over 34,000 subjects to develop the screening methodology and demonstrate its accuracy, clinical value, costeffectiveness, acceptability, and potential to be implemented by healthcare systems throughout Europe.



Medical research project IP Cure B, Horizon 2020

The objective of the EU-funded medical research project IP-cure-B « Immune profiling to guide host-directed interventions to cure HBV infections» is to develop novel curative concepts for chronic hepatitis B (CHB). The project aim is to improve the cure rate of CHB by boosting innate immunity with immune modulators and stimulating adaptive immune responses with a novel therapeutic vaccine. Researchers are also identifying immune and viral biomarkers for patient stratification and treatment response monitoring. Integration of biological and clinical data enable models for the best combination treatment and effectiveness of novel curative therapies with respect to disease spectrum and patient heterogeneity. The preclinical platform will be evaluated in humanised mice, combining immune-modulatory strategies to stimulate innate immunity, rescue exhausted HBV-specific T cells and generate anti-HBV adaptive responses. Proof of concept is to obtain in a clinical trial of a combination of novel compounds stimulating innate immunity.



Medical research project Liverscreen, Horizon 2020

The aim of medical research project LiverScreen is to develop a targeted screening methodology to identify persons with asymptomatic liver fibrosis and cirrhosis among the general population. This methodology involves:

- 1) identification of groups from the general population at high risk of having chronic liver disease,
- 2) screening their liver stiffness with the innovative transient elastography (TE) technology (until now only validated in patients with known liver disease) for diagnosis, and
- 3) determining the right follow-up screening regime. Within the LiverScreen project



Medical research project FiSplat, European Institute for Innovation and Tehnology – EIT Health:

FibroScan Screening Platform (FiSPlat) assess the presence of significant liver fibrosis with an accuracy at least equivalent to the one of the current FibroScan devices (with a sensitivity of 93% and a specificity of 78% using a cutoff of 9.2 kPa). An ergonomic, training procedure, results output and interpretation assistance and an innovative business model, makes the technology usable in a cost-effective manner for mass screening by nurses and general practitioners. This allow earlier decision-making and a personalized follow up. All together prevent the progression of the disease to liver cirrhosis, its associated worldwide morbidity and mortality, as well as reduce liver cirrhosis management costs.



Medical research project Decision, Horizon 2020:

The objective of medical research project DECISION is to enhance our understanding, at systems level, of the pathophysiology of decompensation of cirrhosis leading to ACLF or death. For that purpose, project partners perform a multi-omic profiling of already existing large and clinically well characterized cohorts including 2,200 patients

with available standardized biobank samples. The gained knowledge during the process allows the development of prognostic and response tests and of combinatorial therapies tailored to the needs of individual patients or identified groups of patients with acute decompensation of cirrhosis. All these efforts aim to decrease the risk of short-term death of patients with acute decompensation of cirrhosis.

Being part of many medical research projects ELPA representatives took part in many meetings related to the implementation and monitoring of these projects.

Microb-Predict Horizon 2020 research project kick-off meeting

European Foundation for the Study of Chronic Liver Failure (EF Clif) in Barcelona organized the first press conference on the Microb-Predict Horizon2020 research project. Microb-Predict project, which will investigate the human microbiome to identify predictors and mechanisms associated with the development of decompensation of cirrhosis and progression to acute-on-chronic liver failure (ACLF) and death. The Microb-Predict is one of the three projects, out of 27 research projects which have applied, that European Commission has chosen to fund. The project will gather 22 partner organizations working in different fields. ELPA was included in preparatory work and is scheduled to participate in all important parts of the project.

Out of 22 consortium partners, 18 of them were present in Barcelona and they unanimously elected ELPA as part of Microb-Predict Impact Board. Impact Board will monitor the communication and dissemination of the all 22 consortium partners and will report to the management of the research

project. ELPA was represented by the President Marko Korenjak who has presented ELPA's work and benefits that the patients will receive from this project. European Commission representative Mr. Dirk Hadrich, who was present at the meeting, has commented during the meeting that the inclusion of the patients' voice was one of the four important factors that led the European Commission to decide to fund this project.

LiverHope project meeting

LIVERHOPE MEETING FOR A CLINICAL TRIAL DESIGN FOR PATIENTS WITH DECOMPENSATED CIRRHOSIS

Meetings took place in Barcelona, Spain from 3th to 6th of June. The LiverHope project meeting had three parts – clinical, management and dissemination part at the end. Marko Korenjak presented ELPA activities in the dissemination of the results of LiverHope project. The dissemination reach we have had wasn't a surprise given the fact that we are the voice of European liver patients, so it was expected that ELPA's part in this project would gradually increase. Our task was to show to the EU Commission our results. The purpose of the LiverHope clinical meeting was to reach consensus on a recommendation for crafting clinical research for patients with decompensated cirrhosis. ELPA was represented by ELPA President, Marko Korenjak. As per ELPA's involvement in all the steps of the project and as it is agreed at the meeting, the final paper will also include the voice of the patients.

FiSPlat EIT project has been approved

Among 276 applications across all pillars which went through strict eligibility checks and intensive remote and face-to-face evaluations with external experts, European Institute for Innovation and Technology (EIT) approved 3 year project as continuation of

LiverScreen project in 2018. ELPA is responsible for communication, dissemination and educational activities. EIT especially congratulated ELPA for an outstanding proposal for 2020 Business Plan and added that our application has passed all stages of the selection process - something that ELPA and our cross-EU team can be very proud of. The project officially starts from the 1st of January 2020.

The Lancet Gastroenterology and Hepatology journal press release

Great results from the LIVERHOPE Safety Study recently published in The Lancet Gastroenterology and Hepatology journal. One of the most prestigious journals in the world - The Lancet - published in the section about Gastroenterology and Hepatology the results of the safety study from the Horizon 2020 research project LiverHope where ELPA is one of the consortium partners. We shared this publication on our social media channels and we are proud of the exceptional work that liver researchers are doing in Europe.


A woman is shown from the chest up, holding a smartphone. The image is overlaid with a semi-transparent orange filter and various social media icons. The icons include a heart, a refresh symbol, a Wi-Fi signal, a speech bubble, a star, a cloud with a download arrow, a music note, a location pin, and a share symbol. The background is a soft-focus portrait of the woman's face and hair.


Social Media **activities**

2019 report by Milan Mishkovikj

ELPA Website - 2019 Visits

LAST 30 DAYS:	LAST 365 DAYS:	TOTAL:
4,124	47,317	47,317

	FOLLOWERS	LIKES
 Twitter	5.626	22.541

	FOLLOWERS	LIKES
 Facebook	2.078	2157

	IMPRESSIONS
 Twitter & Facebook	32.000.000 +

2019 Social media Campaigns:

- World Cancer Day
- Rare Diseases Day
- EASL-ELPA symposium
- Spring Testing Week
- International Nash Day
- World Hepatitis Day
- EndHep Europe initiative
- International PBC Day
- PSC awareness Day and week
- 1st Patients Safety Day
- October Liver Cancer Month

ELPA is among the top 10 social media influencers 2019 regarding:

The #SpringTestingWeek Influencers

Top 10 by Mentions

- @EuropeLiver 545
- @EU_Health 523
- @Marko_Korenjak 462
- @WHO_Europe 280
- @EuroTestWeek 272
- @IntegrateJA 255
- @Hepatosplit 203
- @V_Andriukaitis 172
- @JHepatology 171
- @EASLnews 154

The #EndHep Influencers

Top 10 by Mentions

- @EuropeLiver 326
- @EU_Health 294
- @Marko_Korenjak 276
- @V_Andriukaitis 174
- @WHO_Europe 158
- @ECDC_HIVAIDS 150
- @IntegrateJA 147
- @ECDC_EU 141
- @LiverHope_h2020 123
- @EMCDDA 119

The #NOhep Influencers

Top 10 by Mentions	Top 10 by Tweets	Top 10 by Impressions
<ul style="list-style-type: none"> @NO_hep 357 @EuropeLiver 242 @EU_Health 228 @Marko_Korenjak 223 @hepatosplit 192 @WHO_Europe 191 @Hep_Alliance 99 @WHO 92 @coryjameslondon 62 @Gilleschall 62 	<ul style="list-style-type: none"> @NO_hep 110 @EuropeLiver 66 @_yashendra 64 @gordo_78 49 @hepar_center 44 @HeparCenter 41 @elva200764 37 @HepFoundation 34 @DanTam_rnhealth 21 @Marko_Korenjak 21 	<ul style="list-style-type: none"> @NO_hep 369.5K @EuropeLiver 330.5K @HepFoundation 235.2K @joekajoha 100.4K @Hep_Alliance 185.5K @cdchep 105.5K @SmilesParker 101.5K @stephenpaimar 94.1K @rnhealth 65.5K @OlyGuseva 61.6K

The Numbers







- 3.295M Impressions
- 1,680 Tweets
- 473 Participants
- 2 Top Tweets/Retweets
- 4 Top Tweets/Retweets

Twitter data from the #NOhep hashtag from Tue, April 23rd 2019, 12:20PM to Wed, May 22nd 2019, 12:20PM (Europe/Warsaw).

symplur











The #NAFLDsummit Influencers

Top 10 by Mentions


-  @EASLnews 27
-  @EuropeLiver 17
-  @WHO_Europe 9
-  @EU_Health 9
-  @kyriakidestella 9
-  @JonathanStineMD 6
-  @EFPIA 5
-  @LITMUS_IMI 4
-  @QAnstee 4
-  @IMI_JU 4

The influencers of #ILC2019











Top 10 by Mentions

-  @EASLnews 85
-  @HepatitisEurope 26
-  @AmDiabetesAssn 17
-  @genfit_pharma 16
-  @Marko_Korenjak 16
-  @tomhemmingk 13
-  @EASLedu 12
-  @elpe 12
-  @agenceANRS 11
-  @Moedas 11

← #NOhep Healthcare Social Medi...
www.symplur.com











 Tweet

Top 10 by Impressions

-  @EuropeLiver 535.1K
-  @NO_hep 366.9K
-  @HepBFoundation 214.5K
-  @alhands 206.9K
-  @jojokejohn 188.4K
-  @Hep_Alliance 185.3K
-  @SmilesParker 101.1K
-  @stephenpalmer 94.1K
-  @mnhealth 68.9K
-  @JVLazarus 67.2K


← #NASH Healthcare Social Media...
www.symplur.com

Top 10 by Impressions

-  @kylejnorton 1.9M
-  @_Woman_health 1.3M
-  @juliana_evans 828.1K
-  @HYPEBEAST 638.7K
-  @EuropeLiver 611.0K
-  @nashsocial 342.2K
-  @GileadSciences 271.0K
-  @fintechna 172.9K
-  @AASLDtweets 170.8K
-  @RIBA 156.8K

High level People who reacted to ELPA's tweets:












ELPA
structure

ELPA Governing Board 2019




The European Liver Patients' Association (ELPA) is a not-for-profit association for viral hepatitis and other liver diseases. ELPA is directed by a Governing Board, which is elected by its members at the Annual General Meeting.

-  Marko Korenjak, M.A., President
-  Julio Burman, Vice-President
-  Ivana Dragojević, Vice-President
-  Dr. Tove Frisch, M.D., Vice-President
-  MSc. Tatjana Reić, Treasurer
-  Dr. Teresa Casanovas Taltavull, M.D.
-  Marinela Debu
-  MSc. Milan Mishkovikj
-  Dr. Gamal Shiha, M.D.


ELPA Scientific Committee

-  Dr. Teresa Casanovas-Taltavull, M.D., Leader of the ELPA Scientific Committee
-  Dr. Helena Glasova, M.D.
-  Dr. Vesna Lučić-Samardžija, M.D.
-  Mr. Vladimir Lozanovski, M.D.
-  Dr. Sabela Lens, M.D.
-  Dr. Reham Soliman, M.D.
-  Dr. Salvatore Piano, M.D.

ELPA Supervisory Board Committee

-  Richard Hall
-  Emilia Dos Santos Rodrigues
-  Ole Jorgen Lygren

ELPA Secretariat

-  Veronika Všetíčková
-  Beatrice Credi

ELPA Working Groups

In 2019, ELPA had officially two Working Groups respectively about Rare diseases and Hepatitis elimination.

ELPA Working Group on Rare diseases

The Group is led by Sindee Weinbaum in collaboration with some ELPA member's representatives from Norway and from the UK. In 2019 the Group met with Patients Advocacy groups with Pharmaceutical companies at the EASL 2019 Congress in Vienna, Austria. It also had contact with Cymabay Therapeutics in New York regarding Clinical Trials. During the PSC Partners Seeking a Cure conference in Mayo Clinic Minnesota, USA it organized meetings with Pharmaceutical companies such as High Tide Therapeutics, Cymabay but also with leading doctors in the field of PSC. It also Attended PSC Forum PSC Endpoints working group for clinical trials video conference, the AASLD conference in Boston, USA where it got in contact with pharmaceutical companies such as Gilead, Intercept, High Tide, Cymabay, the PSC Forum in Boston, USA and the PBC Network working group in Edinburgh, Scotland-UK.



ELPA Working Group on Hepatitis B elimination

ELPA has been working on Hepatitis elimination since its creation. Knowledge and awareness about Hepatitis B (HBV) have always been at the core of the association and a priority for its members. In 2019, an ELPA Working Group has been formally established and it is led by Marinela Debu and Ivana Dragojevic. During the past months, the Working Group has collected updated and relevant information in order to push forward Hepatitis B elimination and achieve this goal. As we all are aware that chronic HBV is still a life-lasting diagnosis, the Group had gathered data on the lives of HBV patients in order to choose which particular project can have the most impact to improve the living conditions of such patients. The aim of this particular Group is to provide tools for chronic HBV patients so they can live their lives like any other human being, but smartly and safely.

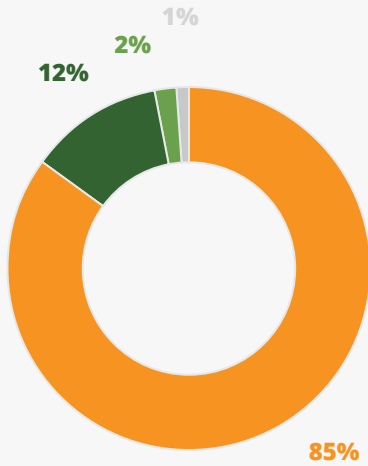


During 2019 other areas related to liver diseases has been investigated by ELPA. The official creation of additional groups will follow in 2020.

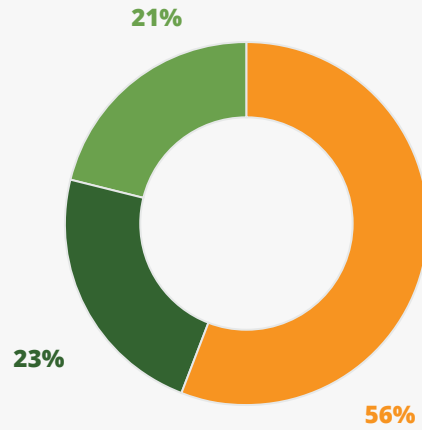


Financial
Accounting and
Transparency

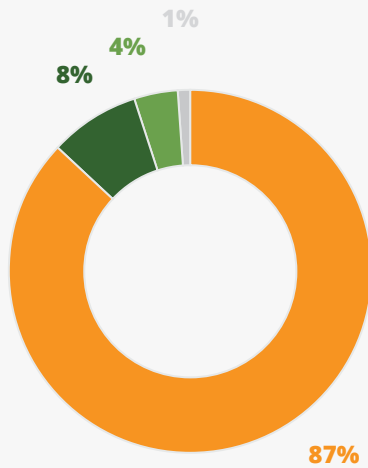
2018 - INCOME



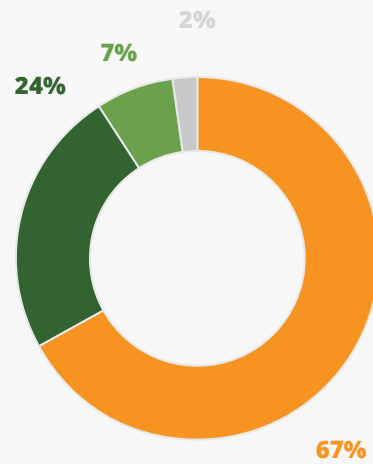
2018 - EXPENDITURES



2019 - INCOME



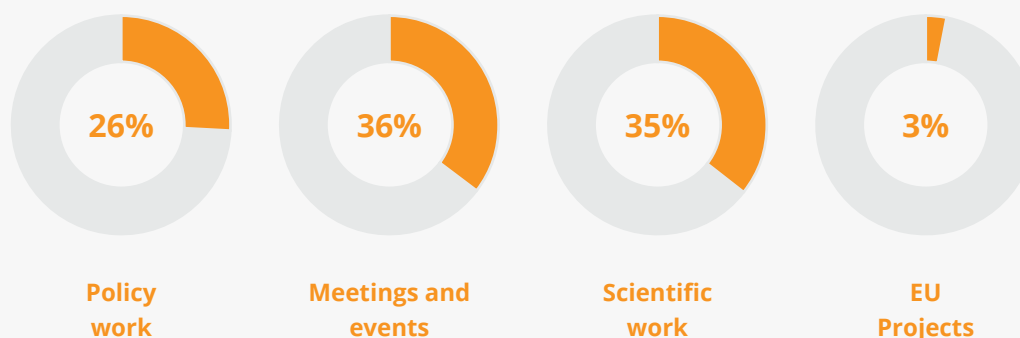
2019 - EXPENDITURES



- Membership fee
- Sponsors and donors
- EU Projects
- Other

- ELPA work
- Operational expences
- Wages and fees
- Depreciation

Cost of ELPAs work in 2019



Fiscal Balance

FISCAL BALANCE Draft print

p. 1

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ELPA

Financial year : 2019 02/06/2020 09:45:36

ASSETS			LIABILITIES		
		EUR			EUR
2	FORMATION EXPENSES, FIXED ASSETS ANI	Balance	1	CAPITAL, PROVISIONS AND AMOUNTS PAYA	Balance
231	Plant, machinery and equipment: freehold	66 940.00	1311	Unavailable reserve - FibroScan	60 246.00
2319	Amounts written down (-)	-6 694.00	140	Profit carried forward	502 361.77
2411	ICT	7 777.46	151	Funds allocated for covering social liabilities	50 000.00
241109	ICT - Amounts written down (-)	-6 635.46			
		61 388.00			612 607.77
4	AMOUNTS RECEIVABLE AND PAYABLE WITH	Balance	4	AMOUNTS RECEIVABLE AND PAYABLE WITH	Balance
404	Income receivable	85 205.00	440	Trade debts: suppliers	3 137.46
4042	Suppliers with Debetsaldo	2 358.56	444	Trade debts: invoices to be received	16 609.69
		87 563.56	451	VAT payable	11 030.15
			454	Social security contributions	-2 320.24
			455	Remuneration	3 112.24
			456	Holiday pay	1 411.23
			492	Accrued charges	6 383.20
					39 363.73
5	CURRENT INVESTMENTS AND CASH AT BAI	Balance			
5500001	ING Current Account	123 296.16			
5500002	ING Savings Account	51 092.77			
5500003	ING Current Account CHF	34 373.20			
5500004	ING Current Account USD	211 574.00			
5500006	ING Current Account GBP	35.09			
5500007	ING Deposit account	2 258.94			
5500008	ING Current Account DKK	19 542.50			
5500009	KBC Brussels Business Concenience Account	55 948.79			
5500010	KBC Brussels Business PRO Account	4 893.75			
570	Cash in hand	4.74			
		503 019.94			
TOTAL ASSETS		651 971.50	TOTAL LIABILITIES		651 971.50

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DEBIT		EUR	CREDIT		EUR
60	Raw materials, consumables and goods for resa	Balance	70	Turnover	Balance
60200141	Policy Work - NASH - Travel & transfer costs	8 328.47	702000	Membership fee	2 700.10
60200142	Policy Work - NASH - Accomodation	4 561.25	7020012	Core funding	52 005.00
60200143	Policy Work - NASH - Subsistence	1 807.89	702002	Reimbursements	12 515.59
602001431	Policy Work - NASH - Subsistence - Contributio	1 575.00	702006	Revenues 2018	-317.49
60200144	Policy Work - NASH - Meeting room	2 571.25	702013	Projects - Advisory Board Meeting	70 980.00
60200145	Policy Work - NASH - Fees	121.00	7020131	Symposium at ILC	8 200.00
60200146	Policy Work - NASH - Printed material	745.00	7020139	MICROB-PREDICT - management and organis	28 000.00
60200151	Policy Work - Support mtgs - Travel/transfer cos	3 613.87	702014	Projects - NASH summit	49 525.00
60200152	Policy Work - Support mtgs - Accomodation	380.00	7020151	Projects - ELPA@Home	80 190.32
60200153	Policy Work - Support mtgs - Subsistence	143.89	702019	HCC	30 000.00
602001531	Policy Work - Support mtgs - Subsistence - Con	2 025.00			
60200161	Policy Work - Stakeholders - Travel/transfer cos	397.95			333 798.52
60200162	Policy Work - Stakeholders - Accomodation	3 138.77			
60200163	Policy Work - Stakeholders - Subsistence	3 403.00			
60200164	Policy Work - Stakeholders - Venue	605.00	74	Other operating income	Balance
60200165	Policy Work - Stakeholders - Event manager	394.79	744	Reimbursement Social Security	97.20
60200167	Policy Work - Stakeholders - Other	469.48			
60200171	Policy Work - cross over - WHO	3 143.02			
602001711	Policy Work - cross over - Others	3 676.01			97.20
6020017111	WHO - Subsistence - Contributinal compensat	1 125.00			
60200172	Policy Work - cross over - EU Institutions	4 669.94			
602001721	Policy Work - cross over - EU Institutions - Cont	1 050.00	75	Financial income	Balance
60200173	Policy Work - cross over - VHPB	115.00	751	Income from current assets	58.26
602001731	Policy Work - cross over - VHPB - Contributiona	600.00	755	Unrealized exchange gains foreign currencies	5 770.67
60200174	Policy Work - cross over - EASL	236.16	757	Obtained discounts of payment	0.10
602001741	Policy Work - cross over - EASL - Contributinal	600.00	758	Gains resulting from rounding off	0.36
60200177	Policy Work - cross over - EPF	380.00			
60200178	Policy Work - cross over - HIV community	442.20			
602001781	Policy Work - cross over - HIV community - Con	525.00			5 829.39
60200179	Reimbursement	213.23			
602001791	Gilead - Contributinal compensation	375.00			
6020018	Policy Work - Supplemental policy consultancy	7 727.40	78	Transfer from untaxed reserves and deferred tax	Balance
6020019	Policy Work - Representation	21.48	782	Transfer Reserve FibroScan	6 694.00
6020032	AGM - Travel & transfer costs	8 606.07			
6020033	Accomodation	20 902.97			6 694.00
60200331	AGM - Accomodation - Hotel	-56.70			
6020034	AGM - Subsistence	3 853.85			
60200341	AGM - Subsistence - Contributinal compensati	4 125.00			
6020035	AGM - Meeting room	2 375.55			
6020036	AGM - Booth	6 477.07	79	APPROPRIATION ACCOUNT	Balance
60200362	AGM - Booth furniture	24.80	790	Positive result from the previous financial year	709 761.65
6020037	AGM - Badges	2 100.00			
60200391	AGM - Promotion - Banner	1 966.65			709 761.65
60200392	AGM - Promotion - Annual report	11 525.25			
6020040	AGM - Organizational costs	2 500.00			
6020081	Board Mtgs - Travel & transfer costs	233.80			
6020082	Board Mtgs - Accomodation	3 673.05			
6020083	Board Mtgs - Sbusistence	1 004.67			
60200831	Board Mtg - Sbusistence - Contributinal compe	560.00			
6020084	Board Mtgs - Meeting room	2 037.00			
6020085	Board Mtgs - Event manager	300.10			
6020111	Fundraising - Travel & transfer costs	8 175.51			
6020112	Fundraising - Accomodation	6 214.86			
6020113	Fundraising - Subsistence	1 322.68			
60201131	Fundraising - Subsistence - Contributinal comf	2 400.00			
6020114	Compensation	12 655.00			
6020115	Other	100.89			
6020133	Scientific work - Support	29.58			
60201352	Scientific work - EMA - Travel	286.00			
602013521	Scientific work - EMA - Travel - Contributinal cc	300.00			
60201361	Scientific work - Travel & transfer costs	5 612.55			
60201362	Scientific work - Accomodation	3 031.30			
60201363	Scientific work - Subsistence	798.09			
602013631	Scientific work - Subsistence - Contributinal co	2 400.00			
60201364	Scientific work - admin supp & Other	557.00			
60201391	Scientific work - ELPA symp -Travel/transfer cos	415.65			
60201396	Scientific work - ELPA symp - Printed material	804.65			
60201421	Scientific work - Advisory - Travel/transfer costs	18 945.32			
60201422	Scientific work - Advisory - Accomodation	16 892.97			
60201423	Scientific work - Advisory - Subsistence	10 422.09			
602014231	Scientific work - Advisory - Subsistence - Contri	5 850.00			
60201424	Scientific work - Advisory - Conference package	3 868.44			
60201425	Scientific work - AdvisoryScientific support	677.60			
60201426	Scientific work - Advisory - Management fee	1 413.87			
60201427	Scientific work - Advisory - Other	2 971.05			
6020143	Scientific work - HCC	121.43			
60201431	Scientific work - HCC - Contributinal compensat	150.00			
6020145	Scientific work - NASH	2 172.91			
60201451	Scientific work - NASH - Contributinal compens	1 050.00			
6020147	Scientific work - SC management	8 400.00			
60202111	ELPA Strategy - Travel & transfer costs	489.88			
60202112	ELPA Strategy - Accomodation	3 273.52			

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60202113	ELPA Strategy - Subsistence	2 776.73
60202114	ELPA Strategy - Venue	355.26
60202115	ELPA Strategy - Event manager	345.01
6020221	Hep-CORE - Organization & management	43 560.00
6020252	ELPA home - Romania	9 992.43
60202521	ELPA home - Romania - Contributitional compen:	600.00
6020253	ELPA home - Croatia	412.00
6020255	ELPA home - Poland	14 295.85
60202551	ELPA home - Poland - Contributitional compensa	225.00
6020257	ELPA home - Turkey	10 106.00
60202571	ELPA home - Turkey -Contributitional compensat	300.00
60202631	PR & promotion - Travel & transfer costs	85.00
60202631	PR & promotion - Subsistence - Contributitional c	75.00
602027	Rest costs last year	898.40
602027111	Rest costs last year - NASH Summit - Contributi	675.00
602028	Next year's costs	20 352.00
602029	LIVERHOPE - management & organisation	1 228.78
60202921	LIVERHOPE - management & organisation	525.00
60202931	LIVERHOPE - management & organisation	330.00
6020311	MICROB-PREDICT - management & organisati	535.54
60203111	MICROB-PREDICT - management & organisati	525.00
6020312	MICROB-PREDICT - management & organisati	8 300.00
6020313	MICROB-PREDICT - management & organisati	312.55

370 003.57

61	Services and other goods	Balance
6100	Rent and rental loads	11 172.00
61210	Communication - Postal costs	149.19
612111	Communication - Telephone - Brussels office	2 289.83
612112	Communication - Telephone - Virtual office	443.60
61214	Communication - Assistant	3 600.00
61220	Office Cost - Office equipment	1 594.06
6122011	Office Cost - Travel & transport	950.00
6122012	Office Cost - Accomodation	1 003.37
6122013	Office Cost - Subsistence	256.91
61220131	Office Cost - Subsistence - Contributitional comp	375.00
6122014	Office Cost - Other	229.90
61224	Web Hosting	141.65
612242	Comunication/Web/Domain & website renewal	1 589.54
61225	Communication - Social media	5 040.00
612912	Back Office - Administrative assistant	24 100.00
612915	Back Office - Admin support secretariat	36 000.00
612917	Back Office - Support Treaseurer	12 000.00
613001	Back Office - Accounting Fees	9 055.64
613002	Back Office - Lawyer Fees	5 100.58
6130021	Back Office - Audit	103.15
6130022	Back Office - Incurance	199.10
6130023	Back Office - Health Service	119.65
6130034	Staff - Office manager	3 832.04
6130035	Staff - Administrator	1 752.56
613004	Social Security Fees	3 486.05
6135	Back Office - Legal Publications	132.98
61531	Back Office - Travel & transport	2 053.01
61532	Back Office - Accomodation	536.42
61533	Back Office - Subsistence	687.64
615331	Back Office - Subsistence - Contributitional comp	2 175.00
61534	Other	782.72

130 951.59

62	Remuneration, social security costs and pensior	Balance
6202	Salaried staff	62 928.34
6206	Aangegeven voordelen van alle aard	-12.00
6209	Tft Salary - projects	-13 352.57
6212	Employer's contribution for social security	1 129.79
623	Other personnel charges	127.75
625	Holiday pay	1 411.23
6259	Holiday pay - return	-10 509.29

41 723.25

63	Depreciation, amounts written off and provisions	Balance
6302	Depreciation of tangible fixed assets	6 694.00
6302411	Depreciation of tangible fixed assets	2 592.48

9 286.48

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65	Financial charges	Balance
655	Unrealized exchange losses foreign currencies	6.15
658	Various financial charges	1.00
6590	Bank charges	1 846.95
		1 854.10

69	Appropriation account	Balance
692	Positive result to be transferred	502 361.77
		502 361.77

TOTAL DEBIT

1 056 180.76

TOTAL CREDIT

1 056 180.76

Financial Transparency

Publishing financial reports

All financial reports of ELPA from 2007 are published every year and can be found here: <https://elpa.eu/finance-and-transparency/>.

Statutory audit for 2018, 2019 and 2020

ELPA is currently under external statutory auditing processes that need to be done for a minimum of 3 years. The audit is done by an external, independent, certified auditor for Belgium and Nederland from Alerte Bernard Advies en Interim. Audit reports are published every year at the ELPA web page and can found here: <https://elpa.eu/statutory-audit/>.

Acknowledgments

ELPA is thankful to all its members and numerous volunteers that have helped us accomplished our goals in 2019. We are also thankful to all our stakeholders who have been supporting our endeavors in fighting the liver disease over the years.

In 2019 ELPA received grants as well as, in some cases, in-kind support, from the following companies:



