



Annual Report 2017



European Liver
Patients' Association

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 14th 2005 during the annual conference of the European Association for the Study of the Liver (EASL) and now has 34 members from 27 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 specialist 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

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FOREWORD OF THE PRESIDENT AND THE CHIEF EXECUTIVE OFFICER

Tatjana Reic, President of ELPA



We are currently living in a time when great changes are affecting the way we live our life. Whole world as we know it is making a turn and adopting a new way of thinking. So does the healthcare. It is changing and our task is to make sure that during these changes, patients are put in the centre of a healthcare system. Last year for us in ELPA meant working hard and finding the best possible answers to these changes

that are coming into our view, strengthening further patients' voice in Europe. It is satisfying to look back on 2017 and more than 50 different activities we have carried out, several advisory boards we have joined and our expanded list of partners and stakeholders who continue to give us their tremendous support. Working in line with ELPA strategy for 2017 - 2020, we have directed our activities through three main pillars: empowerment of our membership, advocacy work on EU and national levels and strengthening of our organization. These three pillars have served us as orientation for our work with patients and for patients, trying to reach our shared goals and vision - 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.

Lana Crnjac, Interim CEO



ELPA MEMBERS IN 2017

AUSTRIA	Hepatitis Aid Austria (HAA)
BELGIUM	Vlaams Hepatitis Contactpunt (VHC)
BOSNIA & HERZEGOVINA	The Chronic Viral Hepatitis Patients Association "B18"
BULGARIA	HepActive National Association for Fighting Hepatitis „Hepasist“
CROATIA	Croatian Association For The Liver Diseases (HEPATOS)
DENMARK	Leverforeningen
EGYPT	Association of Liver Patients' Care (ALPC)
FINLAND	The Finnish Kidney and Liver Association
FRANCE	SOS Hépatites Fédération
GERMANY	Deutsche Leberhilfe e.V
GREECE	Hellenic Liver Patient Association „Prometheus“
HUNGARY	Hungarian Association of Chronic Hepatitis Patients „Vimor“
ISRAEL	Israeli Association For The Health Of the Liver "Hetz"
ITALY	Associazione EpaC Onlus
MACEDONIA	Hepar Centar – Bitola Association for health education, prevention and better treatment (HEPTA)
NETHERLANDS	Dutch Liver Patients' Association
POLAND	Star of Hope Foundation
PORTUGAL	SOS Hepatites Portugal
ROMANIA	Patients with hepatic impairment Association of Romania (APAH-RO) Association Sano-Hep
SERBIA	Liver patients' association „Hronos“
SLOVAKIA	Hep Help Klub
SLOVENIA	Slovenian Association of patients suffering from hepatitis Slovenia HEP
SPAIN	Catalan Association of Hepatitis Patients (ASSCAT), National Federation of Sick and Transplanted Liver (FNETH)
SWEDEN	Riksföreningen Hepatit C (RHC)
TURKEY	Living with Hepatitis Association "HEPYAŞAM"
UNITED KINGDOM	British Liver Trust Hepatitis C Trust Liver4Life PBC Foundation
UKRAINE	Stop Hepatitis

2017 HIGHLIGHTS

ELPA activities at ILC 2017



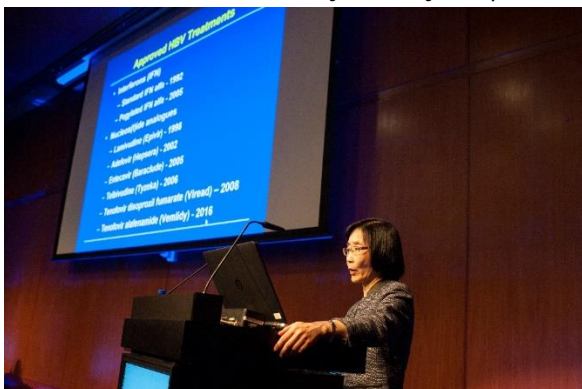
Last year's EASL ILC was held in Amsterdam from 18th to 23rd of April and, just as in previous years, ELPA conducted several activities, including the speech, ELPA President **Tatjana Reic** has delivered at the Opening ceremony.

Clearly stating that if we do not manage to tackle hepatitis elimination in Europe, which is still the richest world region – how we can expect other world regions to take on the challenge, she has sent out several meaningful messages to the audience comprised of esteemed clinicians, patient advocates, industry and other stakeholders.

ELPA President Tatjana Reic speaking at ILC opening ceremony

ELPA Symposium

What have we done so far and how much more should we do? What are our expectations and how attainable are they? This is just a clip from our 2017 Symposium “New Horizons in Liver Disease” programme, which took place during the International Liver Congress™ in Amsterdam on 20th of April. With speakers as **Prof. Anna S. Lok**, President of AASLD, **Prof. Jean-Michel Pawlotsky** and **Prof. Ali Canbay**, at the ELPA symposium we wanted to look at what progress has been made, and what the future looks like for Hepatitis B, Hepatitis C and Autoimmune Liver Diseases. We are delighted that this was the most attended ELPA Symposium so far and the whole ELPA Governing Board would like to thank you for your presence.



Prof. Anna S. Lok, President of AASLD



Ingo Van Thiel, ELPA Scientific team leader



Marko Korenjak, Prof. Ali Canbay Tatjana Reic, Ingo Van Thiel, Anna S. Lok, Prof. Jean-Michel Pawlotsky, Robert Mitchell-Thain and Livia Alimena

Annual General Meeting

Friday 21st in RAI Amsterdam was reserved for our Annual General Meeting. We are happy that last year's fruitful discussion has made large contribution to the meeting and has yielded some valuable decisions. On that occasion the governance presented the Annual report 2016, the accounts for 2016 have been approved, **Marko Korenjak** was confirmed as ELPA Board Member and the budget for 2017 was adopted. These activities were followed by workshop/training on Hep-CORE report.



ELPA members at Annual General Meeting

Elimination of hepatitis B and C in the EU: challenges and opportunities

On the last day of EASL congress, just before the closing session, ELPA President **Tatjana Reic** presented the Hep-CORE report during “Elimination of hepatitis B and C in the EU: challenges and opportunities” session. Once again the audience through their comments and feedback confirmed the importance of this patient led survey and its findings.

First NAFLD - NASH EU Policy Summit

Aiming to point out to a still missing and much needed concrete action across Europe to face the next major public health challenge, NAFLD and NASH, leading European and national policy-makers, decision-makers, experts, medical specialists and patient advocacy groups active in liver diseases, met at the first European-wide NAFLD-NASH Policy Summit. The summit was organized by **ELPA**, in collaboration with **EASL** and was hosted by **Alojz Peterle, Member of the European Parliament (MEP)**.

Speakers and the participants explored potential measures to reduce the burden of the disease and to mitigate the impact that NASH-NAFLD will have on the sustainability of healthcare systems. *The seriousness of NAFLD and the potential impact it will have on healthcare systems needs to be recognized and addressed before we encounter an epidemic across Europe*, stated **Tatjana Reic**, President of ELPA.



NAFLD, which has become the most common chronic liver disorder in Europe and the U.S., and NASH are seen as lifestyle conditions. The socio-economic costs are not fully recognized. Current research suggests that being overweight or obese and metabolic syndromes such as type 2 diabetes and hypertension are common conditions in patients affected by NAFLD. The prevalence

of NAFLD in the general population ranges from 20% to 30% in Europe and will become the leading cause of liver transplantation in the next 10-20 years.



These diseases are not a policy or a treatment priority in the EU. Liver disease strategies are missing or are not implemented across Europe. Against this scenario Carlos Moedas, Commissioner for Research and Innovation stressed the “need to scale up efforts in research and innovation [to] develop simple, cost-effective and non-invasive tests” that will allow to “improve guidance to member states on primary care and better management” he continued.

*This Summit is intended to trigger a serious debate around NAFLD, to increase the policy focus on this imminent public health challenge that Europe is facing, added **Tatjana Reic**. The community needs to take action to establish effective policies for early detection and effective therapies, and put more effort into prevention policies across the European Union.*

Prof Helena Cortez-Pinto, the EU Counsellor at EASL, reminded MEPs that they had a key role to play in prevention but pointed out that they have just missed a rare opportunity to restrict the marketing of junk food to minors when debating the Audio Visual Media Services Directive. “Childhood obesity is the plague of the 21st century and MEPs could have tightened restrictions on marketing to minors”, she said. “Unfortunately they chose not to take this step. They talk the talk but don’t walk the walk.” We are going to spend billions and billions of Euros in the next decades, trying to cure diseases that might have easily been prevented with simple measures, such as those restrictions. She called on MEPs and the Member States to remedy this in the dialogues on the proposal that will start in June or July.

Prof. Helena Cortez-Pinto, the EU Counsellor at EASL and Alojz Peterle MEP



"As Members of the European Parliament we were elected to represent the voice of the European citizens. When it comes to health issues we must therefore speak in one voice with our patients and do everything in our power and position to put NASH-NAFLD challenge in the centre of our policy efforts" MEP Alojz Peterle, stated. One of our high level NASH-

NAFLD Policy Summit supporters, **Mr. Carlos Moedas, European Commissioner for Research, Science and Innovation**, addressed esteemed guests with the video made especially for this occasion.



ELPA at Civil Society Forum

Another important breakthrough for European hepatitis patients - ELPA at EU HIV/AIDS, Hepatitis and Tuberculosis Civil Society Forum (CSF)

We are happy to announce that ELPA in 2017 ELPA was formally approved as member of the new HIV/AIDS, Hepatitis and Tuberculosis Civil Society Forum. EU HIV/AIDS Civil Society Forum has been coordinated and chaired by the **European AIDS Treatment Group (EATG)** and **AIDS Action Europe (AAE)** since its inception in 2005. The CSF has actively promoted the integrated approach to address the epidemics and to raise attention to TB and Hepatitis as mono infections.



Tatjana Reic, ELPA President, has represented ELPA at kick-off meeting at Civil Society Forum, followed by a Think Tank meeting at DG Santé of European Commission in Luxembourg. It was a historic day for European Hepatitis patients, as ELPA President said, since that is the first time ever that ELPA got a seat at Civil Society Forum, where addressing hepatitis patients' needs and problems will now have even greater audience. That meeting was designed in order to discuss and agree on objectives and working methods of the new CSF, including cooperation with the EUHIV/AIDS, hepatitis and tuberculosis Think Tank. During the sessions in 2017 Tatjana Reic has pointed out that out of 40 members of CSF, consisted mostly of persons from public health arena, more than 20 seats are taken by HIV patients' representatives, whilst only three of them are from Tuberculosis and Hepatitis groups. She stressed that this should be changed in order to have all three diseases equally represented.

Second Civil Society Forum meeting in 2017 was held in December, when Tatjana Reic presented ACHIEVE coalition to all the participants, while Prof. Jeffrey Lazarus presented ELPA's Hep-CORE study.

Launch of the ACHIEVE coalition

Launched at an event in the European Parliament on June 7th, the **ACHIEVE** (short for **Associations Collaborating on Hepatitis to Immunize and Eliminate the Viruses in Europe**) coalition calls on the EU to take action to eliminate viral hepatitis B and C by 2030 in the WHO European Region, in line with the WHO Global Health Sector Strategy on viral hepatitis, the WHO Europe Action Plan, which build on and the UN Sustainable Development Goals (SDGs). Chair of the ACHIEVE is **Tatjana Reic**, ELPA President, while the coalition includes the following organisations: **The European Liver Patients' Association (ELPA), the Viral Hepatitis Prevention Board, Hepatitis B and C Public Policy Association, EASL International Liver Foundation, European Aids Treatment Group (EATG), Correlation Network, the World Hepatitis Alliance and the Barcelona Institute for Global Health (ISGlobal).**



Tatjana Reic delivering her speech at ACHEVE coalition launch

Launch of the Hep-CORE results for 2017

Hep-CORE, first patient led study results for 2017 were presented on 9th of November in Brussels among several stakeholders and industry representatives. Results were presented by **Prof. Jeffrey Lazarus** whilst other speakers, such as **Antons Mozalevskis** from WHO and **Katrin Schiffer** from Correlation Network, presented their work and underlined the usefulness of the Hep-CORE study as ELPA stakeholders. This is now the second year that European Liver Patients' Association is shedding the light on national policies on hepatitis B (HBV) virus and hepatitis C virus (HCV), providing a full picture of the level of implementation viral hepatitis B and C policy recommendations in Europe and part of the Mediterranean Basin.

During the 2017, ELPA and Hep-CORE study were presented in the following:

Conferences/meetings	Scientific articles	Posters
1. International Hep C Exchange (IHCE), Paris, 29 January Working towards elimination for all Prof. Jeffrey Lazarus	1. Lazarus JV, Safreed-Harmon K, Stumo SR, Jauffret-Roustide M, Maticic M, Reic T, Schatz E, Tallada J, Harris M, on behalf of the Hep-CORE Study Group Restrictions on access to direct-acting antivirals for people who inject drugs: The European Hep-CORE study and the role of patient groups in monitoring national HCV responses, <i>Int J Drug Policy</i> 2017 Jul 6. doi: 10.1016/j.drugpo.2017.05.054.	1. Lazarus JV, Stumo SR, Safreed Harmon K, Reic T, Maticic M, on behalf of the Hep-CORE Study Group. Access to hepatitis C treatment in Europe: findings from the 2016 Hep-CORE study The International Liver Congress. Amsterdam, 19-23 April 2017. <i>Journal of Hepatology</i> , 2017;66 (1):S408.
2. Hep-CORE launch in Romania, Bucharest, 30 January Presentation to the press and key stakeholders		2. Lazarus JV et al on behalf of the Hep-CORE Study Group Missed opportunities for diagnosing viral hepatitis

ELPA Vice President Marinela Debu, Achim Kautz and Homie Razavi

testing in Europe: a 25-country analysis. HepHIV 2017 Conference: HIV and Viral Hepatitis: Challenges of Timely Testing and Care, P02/01, Malta, 31 Jan-2 Feb 2017.

3. Slovene National Conference on HCV, Ljubljana, 15 March

Monitoring the Slovene Policy Response to Viral Hepatitis

Prof. Jeffrey Lazarus and ELPA Board Member Marko Korenjak

4. Hep-CORE presentation in Denmark, Copenhagen, 20 March

Presentation to selected key stakeholders

ELPA President Tatjana Reic and Prof. Jeffrey Lazarus

5. Hep-CORE presentation in the EU Parliament, Brussels, 22 March

The Challenge of Hepatitis C in Central and South Eastern Europe: Who is at risk and how patients get access to effective screening, diagnosis and treatment.

Public Affairs Director Livia Alimena and ELPA Board Member Marko Korenjak

6. Hep-CORE presentation during ILC2017 Community Summit Meeting, Amsterdam, 19 April

The ELPA Hep-CORE Study Results: Monitoring European policy responses to viral hepatitis

Prof. Jeffrey Lazarus and ELPA members from selected countries

7. Hep-CORE presentation during ELPA Symposium during EASL ILC2017, Amsterdam, 20 April

New Horizons in Liver Disease. The ELPA Hep-CORE Report

Prof. Jeffrey Lazarus

8. Hep-CORE launch in Croatia, Zagreb, 6-7 July

Regional Conference against Hepatitis

Hep-CORE survey and results.

ELPA Vice President Marko Korenjak

9. 4th International HIV/Viral Hepatitis Co-Infection Meeting (IAS). Paris, 22-23 July

Access in High Income Countries: the European landscape

ELPA President Tatjana Reic and Prof. Jeffrey Lazarus

10. Central and Eastern European Meeting on Viral Hepatitis and Co-infection with HIV. Ljubljana, 27-28 September

Hep-CORE study: Management of HBV and HCV infections throughout Europe

Prof. Jeffrey Lazarus and ELPA Vice President Marko Korenjak

OTHER ELPA ACTIVITIES

Member empowerment - Capacity building of our members

ELPA@Home

@Home in Romania

In the very beginning of February, ELPA has launched its new advocacy program ELPA@Home, created and coordinated by our member **Julio Burman**, ELPA@Home Project Leader. The project's launch was accompanied by press conference attended by ELPA's Vice President **Marinela Debu**, Public Affairs Director **Livia Alimena**, Special Policy Consultant **Achim Kautz**, Scientific Team Member **Andrei Baiceanu** and ELPA's associate and friend **Homie Razavie**.

This visit to Romania, not only that it has showed a great response to ELPA@Home program, but it has also served as a good opportunity to meet several key stakeholders in order to advocate for the Romanian Hepatitis strategy, about to be developed in coming years. ELPA's team has also held a fruitful meeting with the **Romanian Minister of Health, Mr. Vlad Voiculescu**.

Also, only one month after launching our **Hep-CORE** project, we took the opportunity of being in Romania and presented their National results and findings on implementation of Hepatitis B and C policy recommendations in Europe.



Marinela Debu, ELPA Vice President



Homie Razavie, CDA

Presentation of ELPA@Home and Hep-CORE survey in Lithuania

Mid of February was reserved for the "Baltic Countries National Strategies towards the elimination of Hepatitis C" conference, held on February 14th. On that occasion **Julio Burman**, ELPA@Home Project Leader, gave a presentation on two significant ELPA ongoing activities: ELPA@Home project and Hep-CORE survey. The conference aimed to show the current situation in countries like Lithuania, Latvia, Poland, Hungary and Estonia, among which, unfortunately, only Latvia has a hepatitis patients' association. Besides the presentations, conference was marked by a fruitful round table discussion where ELPA's Julio Burman participated as well.

@Home in Croatia

During Croatian Hepatitis Days, on July 5th and 6th, one of the most important ELPA's 2017 projects was held in Zagreb. ELPA@Home workshops, under the name of *How to Influence Policy and Public Perception*, took place just prior to Regional Hepatitis Round Table/Meeting where some of ELPA members were present as well. Attendees were able to learn more during workshops held by **Marko Korenjak** and **Julio Burman**, who talked about how to change public perception, how to influence policy, the most efficient way to cooperate and about patients' problems in Croatia.

@Home in Hungary

Another **ELPA@Home** set of trainings were held, this time in Budapest on 20th and 21st of November. ELPA Vice President **Marko Korenjak** and Project Leader **Julio Burman** have held several presentations, as well as facilitated contact with Health Ministry and ELPA Member from Hungary "Vimor". After successful year of ELPA@Home programme and positive feedback from members, ELPA team has been working devotedly on preparing ELPA@Home 2018.

@home in Poland - workshop and Stakeholders meeting

An amazing finish of the ELPA@home program for 2017! On the first day of workshop held by **Marko Korenjak** and **Julio Burman**, participants discussed about how to change public perception, how to influence policy, the most efficient way to cooperate and how to solve patients' problems in Poland. The workshop was held with NGOs that are already in a coalition. Day two of ELPA@home event in Poland was used to hold a Stakeholders' meeting at **the National Institute of public health**, with all major stakeholders of Poland in healthcare present. **Tatjana Reic** moderated the conference together with **Marko Korenjak** and **Julio Burman**. At the Stakeholders' meeting "Poland Declaration on the elimination of viral hepatitis until 2030" was signed, in the presence of more than 10 journalists.

ELPA University

ELPA University Year 2 – closing session

Closing session of ELPA University Impact programme for Year 2 students was held in Sarajevo from 13-15 March. Module 4 was attended by ELPA University students who, on this occasion, acquired knowledge about social media campaigns and its implementation in fighting liver diseases as patients' associations.



ELPA University students



Milan Mishkovikj, ELPA Vice President presenting at ELPA University session

Module 1 of the third year of ELPA University - IMPACT Programme commenced in Budapest from 27 – 30 September. ELPA University is a year-long training programme that has been set up by ELPA to provide knowledge and skills based training to community organisations from countries in Europe that have less developed liver healthcare systems and patient support. The programme focuses on improving attendees' knowledge of liver conditions and their treatment and management. Practical skills training is also provided to support attendees to advocate for improved services and care within their country.

Viral Hepatitis and Your body

Last year's International Training Day programme consisted of a mix of plenary, panel discussion and interactive workshop sessions exploring how the lives of individual patients are impacted at all the stages of the viral hepatitis care continuum. The content for this educational programme is developed and presented by an international faculty of leading clinicians and patient advocates, in conjunction with Gilead Sciences. Key topics covered during the training are: Treatment and cure – Clinical and patient perspectives, Extra-hepatic manifestations and HBV clinical updates.



Advocacy: Influencing and partnering with stakeholders and ...

ELPA at HepHIV conference in Malta

ELPA's President Tatjana Reic participated in **EU Presidency Conference** hosted by the Government of Malta in collaboration with the ECDC, held from 30 January – 2 February. On Wednesday, February 1st, she moderated the first plenary session "**Surveillance and monitoring**

and evaluation of testing" and afterwards participated as a panellist in a Round table discussion: **"Hepatitis C and unequal access to treatment in Europe"**.

The conference in Malta gathered a great number of stakeholders which resulted with numerous meetings like the one with **Charmaine Gauci**, Superintendent of Public Health for Maltese Presidency with whom our President, together with several members of ACHIVE initiative (**Charles Gore, Pierre van Damme, Jeffrey Lazarus, Eberhard Schatz**), discussed Hepatitis priorities in the upcoming Maltese Presidency and further.

NGO Forum at APASL

ELPA's Vice President **Marko Korenjak** participated at NGO Forum organized by The Asian Pacific Association for the Study of the Liver - APASL. The conference whose participants had a possibility to engage in numerous workshops and debates, took place in Shanghai, China from February 15 – 18. During his attendance at the Forum, Marko gave a presentation on ELPA's activities, results and projects such as Hep-CORE study, Liverhope project, ELPA at home programme and many more. Besides holding the presentation he has also met **dr. Paolo Ascoli**, Liverhope project Stakeholder. The conference was closed on 18th after the briefing on the forum's results for all the participants.

MEP Friends of Liver group event in European Parliament

On March 22nd, MEP **Friends of Liver Group** in European Parliament organized **The Challenge of Hepatitis C in Central and South Eastern Europe: Who is at risk and how can patients gain access to effective screening, diagnosis and treatment?** meeting, hosted by **Dr. Cristian Busoi MEP**, who also chaired the meeting, and co-hosted by **Dr. Biljana Borzan MEP** and **Dr. Andrey Kovatchev MEP**.

On that occasion ELPA presented 2016's ground-breaking study Hep-CORE, covering the situation on the ground. The study was presented by **Livia Alimena**, ELPA Public Affairs Director. Meeting was attended by numerous prominent professionals coming from medical, political and patients' sector.

These are some of the key messages carried out by ELPA representatives during the meeting:

We have the unique opportunity to eliminate viral hepatitis B and C in Europe, two viruses which have caused tremendous harm, personal and financial, over the past decades. However, endeavours towards elimination still lack of political support which could encourage a revision of the Dublin Declaration to include all three diseases: viral hepatitis B and C, tuberculosis and HIV. Such a new Declaration would show a political commitment by Member States to implement the WHO hepatitis elimination goal by 2030. – **Tatjana Reic**, President of ELPA.



MEP Friends of Liver group event in European Parliament

EPF Annual General Meeting

Colleagues from European Patients' Forum have held their Annual General Meeting and leadership meeting in the course of 10th and 11th of April, where ELPA was represented by Board Member **Milan Mishkovikj**. We would also like to use this opportunity to congratulate once again to our member **dr. Stanimir Hasardzhiev** whose mandate in the Governing Board of EPF was extended on that occasion.

Engagement with EATG

Marko Korenjak, ELPA Board Member, participated in EATG's Advisory Board meeting in Brussels from May 19th – 20th. Meeting served as a great opportunity not only to meet with ELPA stakeholders, but also to compare the formats of ELPA's ABM with the other ones and, therefore, to adopt better practices.

He has presented ELPA at 10th Multi stakeholder meeting, organized by EATG in Bucharest from 6-8th of October. In this three day meeting, participants could hear presentations of several pharmaceutical companies and NGO's, including EATG, whose focus in the future will be access for treatment for HIV, HBV, HCV and TB.

Participation at EPKF General Assembly

European Kidney Patients Federation has held their 36th General Assembly in Cyprus. We are honoured that ELPA was invited to deliver a presentation on how we organize ourselves in Europe, what we have achieved and how, the funding options we encounter and finally, how ELPA can help in the area of organ donation. This review was given by our Vice President **Angelika Widhalm**, whose experience in the realm of organ donation contributed to the event.

ECDC: 4TH meeting of the Hepatitis B and C network

During Lisbon Hepatitis week 12-16 June, ELPA President **Tatjana Reic** has participated in ECDC (European Centre for Disease Prevention and Control) meeting of the Hepatitis B and C network from June 12-13, where she presented **"Civil Society's expectations of ECDC's future priorities"**.

ELPA President took the opportunity to especially highlight one of the crucial issues in fighting hepatitis – lack of data measurement.

This meeting, which brought together experts from across the EU to discuss how Europe can improve its response to the epidemics of hepatitis B and C with a focus on surveillance, was followed by EMCDDA's and ECDC's joint meeting on 14th of June, aiming to prepare the ground for fruitful discussion and exchange around practical evidence-based strategies, for sharing achievements and examples of good practices and for identifying solutions to common challenges. Participating in the final debate Tatjana Reic conveyed a strong message for ECDC asking them to do the same thing for hepatitis community that they have been doing for HIV community.

ECDC's 1st advisory group meeting: EUROPEAN MONITORING OF HEPATITIS B AND C

ELPA President **Tatjana Reic** was invited to become advisor at expert meeting held on 29th and 30th of November at ECDC premises in Stockholm *Improving the epidemiological assessment: an expert panel meeting to discuss the development of a framework for measurement and monitoring of the estimates on the Hepatitis B/C Continuum of Care.*

During the meeting we were proud to have also learnt that **Hep-CORE** study is recognized as source of data for inclusion in outputs around the monitoring of hepatitis across EU countries, along with reports of WHO, Eurostat, EMCDDA, WHA etc. ELPA is very proud to be able to contribute to the community in such way and appreciates the efforts of all the partners working and supporting **Hep-CORE**.

Data from regional and national monitoring systems have been important in guiding programmes for the prevention and control of infectious diseases including HIV and tuberculosis. However, to date, there has been no systematic data collection at the European level for hepatitis B and C to enable the monitoring of the implementation of the WHO elimination strategy. Since ECDC aims to support EU/EEA countries around monitoring their responses to the epidemics of hepatitis B and C and plans to develop a European monitoring system, they have organized the 1st advisory group meeting as the first step towards the development of this system building upon the significant experience of monitoring HIV and from Member States that have already made progress in this area.

Communicable Diseases Summit in Vilnius and participating EHC AGM

ELPA President **Tatjana Reic** participated in the second **Communicable Diseases Summit in Vilnius**, where she held a key lecture on ACHIEVE coalition, presenting coalition's objectives and work that has been done so far. Parallel with the Summit in Vilnius, **European Haemophilia Consortium have held their Annual General Meeting**, where ELPA President has presented ELPA activities, mission and objectives.

She has also held a meeting with **prof. Massimo Colombo** in order to discuss options for the possible micro-elimination ELPA and EASL joint workshop at ILC 2018 in Paris.

ELPA at World Health Summit 2017

ELPA President Tatjana Reic represented ELPA on this year's World Health Summit, held in Berlin from 15-17th of October. She participated in the exclusive session organized by Portuguese

Parliamentarian Ricardo Baptista Leite

„**Evidence as a policy driver: towards HCV elimination**”, during which she has

delivered a presentation „What matters to patients?, stressing once again the importance of disease awareness, non-discrimination (neither privately nor professionally), of a timely diagnosis and equal access to treatment for the patients. The WHS enjoys the patronage of the



Chancellor of the Federal Republic of Germany **Angela Merkel** and the President of the European Commission **Jean-Claude Juncker**.

ELPA at The Liver Meeting 2017

The Liver Meeting® is the Annual Meeting in the science and practice of hepatology, including the latest findings on new drugs, novel treatments, and the results from pilot and multicentre studies. Last year's Liver Meeting was held in Washington, USA from October 20 – 24. President **Tatjana Reic**, Vice President **Marko Korenjak** and Public Affairs Director **Livia Alimena** represented ELPA among more than 9,500 hepatologists, health professionals, community and patients' representatives and other stakeholders from across the world. During this annual manifestation ELPA team has carried through meetings with high level representatives like **Anna Lock, George Bologna, Tom H. Karlsen, Helena Cortez Pinto, Massimo Colombo and Grégoire Pavillon**. As every year so far, this was also an opportunity to fundraise for the activities for 2018, which is why ELPA representatives have also held meetings with several ELPA supporters.

World Hepatitis Summit 2017

From 1st to 3rd of November hepatitis community gathered in Sao Paolo for the 2nd World Hepatitis Summit, organized by World Hepatitis Alliance in collaboration with World Health Organization. This global biennial summit aims to advance the viral hepatitis agenda and to encourage fruitful discussion among the stakeholders. It is a joint initiative between **World Health Organization (WHO)** and the **World Hepatitis Alliance**, in collaboration with a different host country for each Summit, this time Brazilian government. Together with Dr. Leolin Katsidzira from the University of Zimbabwe, College of Health Sciences, **ELPA President Tatjana Reic** chaired a session **Strategic direction 1: strategic information for focused action**, which aimed to highlight the role and importance of strategic information in planning and monitoring national responses.

Pre-Summit WHA members' general meeting in Sao Paulo

Just before the official start of the **World Hepatitis Summit**, members of World Hepatitis Alliance had a **Pre-Summit member GM** on **30-31 October**. As that meant that a number of **ELPA** members were present in **Sao Paulo** at that time, **ELPA** team took the opportunity and organized a short members meeting where they could have shared their thoughts/opinions/remarks.

VHPB: Prevention and control of Viral Hepatitis in Belgium and Luxembourg- lessons learnt and the way forward

Viral Hepatitis Prevention Board (VHPB) Meeting on "Prevention and control of Viral Hepatitis in Belgium and Luxembourg: lessons learnt and the way forward", took place in Brussels, on 7th and 8th of November with objective to provide an overview of surveillance systems for infectious diseases; review the epidemiological situation on viral hepatitis; give an overview of the current prevention and control measures on viral hepatitis; review the possible implementation of



new prevention strategies, control measures and monitoring systems; discuss the development, the enrolment and the implementation of a National hepatitis plan; assess the needs to achieve the goal of eliminating viral hepatitis as a major public health threat by 2030 as defined by WHO's Regional office for Europe; discuss successes, issues and barriers to overcome, and the way forward. As VHPB's Advisor, ELPA President **Tatjana Reic**, represented ELPA on this occasion and has co-chaired first session with **Prof. Pierre Van Damme**

ACHIEVE Stakeholder dialogue and Workshop

Shortly after the World Hepatitis Summit some of the most prominent hepatitis community advocates gathered in Brussels for ACHIEVE coalition Stakeholder dialogue and workshop. This two day meeting was organized in two parts – first part gave the floor to coalition's observers **Dr. Antons Mozalevskis**, WHO Europe, **Dr. Erika Duffell**, ECDC, **Dr. Dagmar Hedrich**, EMCDDA, **Jean-Luc Sion**, European Commission, and **Ricardo Batista Leite** UNITE to share their updates and news on the work towards elimination. Second part of the meeting meant the

discussion between coalition members through which they have set the main activities for the upcoming 2018. Meetings were chaired by ELPA President Tatjana Reic and co-chaired by **Prof. Pierre Van Damme**. ELPA was represented by ELPA President **Tatjana Reic** and Policy Officer **Lana Crnjac**.

More Trust, More Data, Better Health

Policy Officer **Lana Crnjac** attended the meeting on data, ethics and innovation in health in European Parliament and organized by Microsoft. Moderated by **Robert Madelin**, Chairman of Fipra International and former Director-General of DG SANTE and DG CONNECT and hosted by **Seán Kelly** MEP, this meeting gave a promising insight into the future of use of data in the healthcare surroundings. The European Union's DSM and Health agendas are addressing areas to work towards this common goal, improve the free flow of health data, allowing patients to access and transfer health records across the EU and improve cross-European research for societal benefits.

Meeting with Cristian - Silviu Busoi MEP

ELPA President **Tatjana Reic** and Policy Officer **Lana Crnjac** in November met with **Cristian - Silviu-Busoi MEP**, chair of the European Parliament "Friends of the Liver" group. During the meeting ELPA representatives presented some planned ELPA activities for 2018, as well as held a fruitful discussion on the conclusions from World Hepatitis Summit.

3rd Technical Advisory Group Meeting for the Georgia HCV elimination programme

As a member of Technical Advisory Group (TAG), President **Tatjana Reic** participated in 3rd Hepatitis C TAG Meeting, held in Tbilisi, Georgia on November 30 - December 1, 2017.

This high level meeting was hosted by Georgian government and its representative Dr. Davit Sergeenko, Minister of Labour, Health and Social Affairs (MoLHSA) with guest speakers such as Mr. Ian C. Kelly, US Ambassador in Georgia and Dr. Zsuzsanna Jakab, WHO Regional Director for Europe. Over the two day presentation of results of Georgia's programme on HCV elimination **ELPA President** has moderated the following sessions: **Promote Advocacy, Awareness, and Education, and Partnerships for HCV-Associated Resource Mobilization and TAG Recommendations and 2018 Priorities** as well as participated in revision of last year's results and producing a set of recommendations for 2018 priorities.

Call to action: Organ donation and transplantation Across the EU

A second meeting on Organ donation and transplantation Across the EU, as a part of the PHA's Call to action campaign, was held in January and was attended by ELPA's Vice President **Angelika Widhalm** and Policy Officer **Lana Crnjac**. Besides ELPA, the meeting was also attended by European kidney Health Alliance, European Kidney Patients' Association, European Federation of Allergy and Airways Diseases Patients' Associations, European COPD Coalition, Donor and Transplantation Institute and Marketing Public Affairs.

To remind you, PHA Europe decided to develop Call to Action to address issues such as shortage of organs, long waiting lists, high mortality, lack of awareness, understanding in the general population and, in some countries, lack of surgery facilities. Call to action is a cross-condition transversal campaign where organizations with the same problems could advocate for change together.

Patient-MedTech Workshops & Conference on Nutrition

Marko Korenjak, ELPA Vice President participated in a conference on patients' nutrition *Towards a renewed patient agenda on nutrition for the period 2018 - 2021*, organized by European Patients' Forum. The event focused on identifying nutritional needs of complex patients, role of the physician in patients' nutrition and gave an insight from a patient perspective, among which was Marko Korenjak who talked about the importance of nutrition for liver patients.

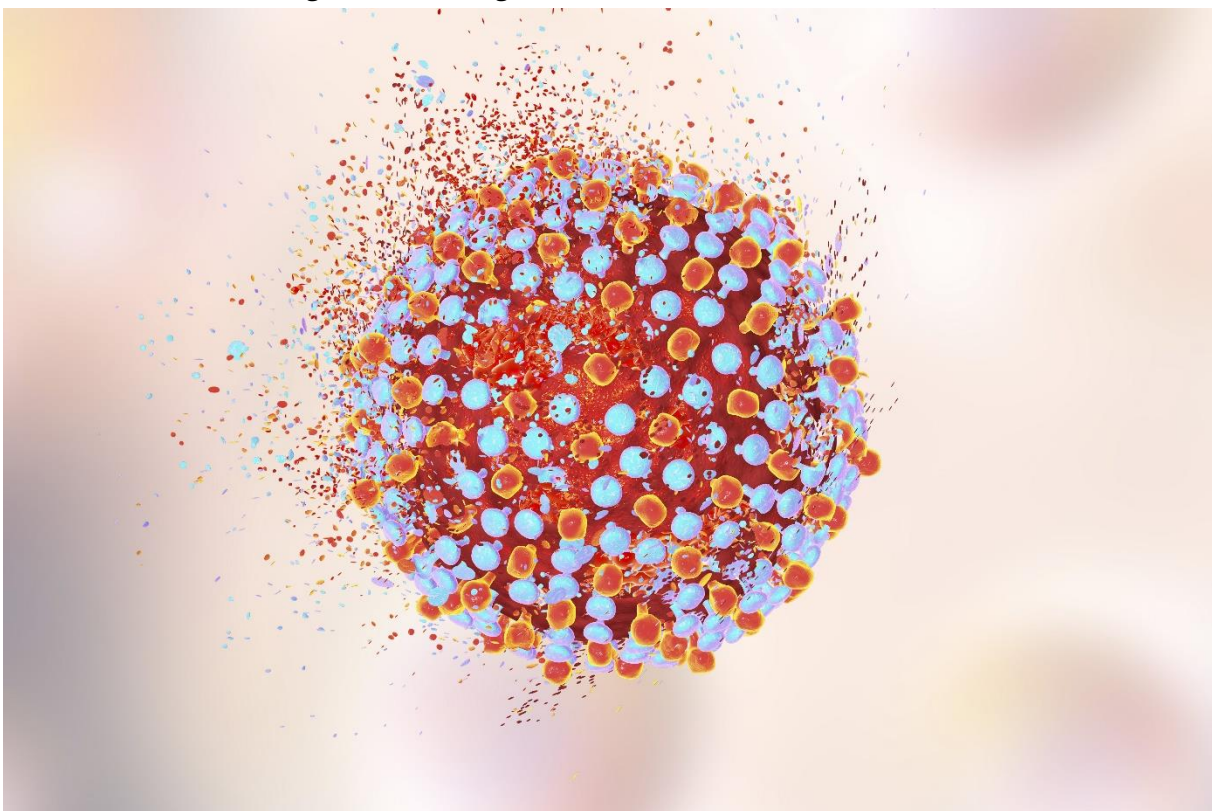
European Patients Forum (EPF) Access Campaign

Milan Mishkovikj, **ELPA Vice President**, has presented ELPA at the launch of the EPF Access Campaign Meeting in Brussels on 6th of December. At the panel discussion it was raised the topic of elimination and access of medicines for hepatitis. During its closing Conference held at the European Parliament, EPF presented its Roadmap and called for political change to ensure that the rights of all patients are respected, to fight the health inequalities that persist across the EU and to make health a priority in all policies at national and EU levels.



ELPA's response to Cochrane study

In June 2017, the Guardian has published the article "Miracle hepatitis C drugs costing £30k per patient 'may have no clinical effect'", referring to the Cochrane Systematic Review on DAA-Based Treatment of Chronic Hepatitis C and their conclusion that such treatment may clear virus from blood, but there is no evidence they prevent harm or save lives. As an organization that works to ensure better liver patients' right, ELPA has joined hepatitis community worldwide in their resolute answer to this misleading media coverage.



We believe conclusions set out in Cochrane research on effectiveness of antiviral therapy are misinforming general public, national decision makers as well as 71 million[1] people infected with chronic hepatitis C globally. On contrary to Cochrane research, recent studies "demonstrate that

oral antiviral treatment for patients with hepatitis C who also have cirrhosis substantially decreases mortality and morbidity". (Cheung et al Journal of Hepatology 2016).

Scientific, Human Health, Husbandry, and Socio-Economic Aspects of Antibacterial Resistance: Time to Act'

Conference Time to Act was held on 28 June in European Parliament, focusing on the implications of the rapidly growing threat of antibacterial resistance (ABR) and the measures needed to immediately halt the spread of ABR both in Europe and globally. Keynote address was given by **Dr Vytenis Andriukaitis, European Commissioner for Health and Food Safety**, during which he underlined European Commission's commitment in tackling ABR for which European Parliament asserted that would become the world's leading cause of death. On behalf of ELPA this conference was attended by Policy Officer **Lana Crnjac**.

The patient journey: Improving quality of life with people living with chronic diseases

On June 28, Belgian Politico has organized a deep-dive discussion: *The patient journey: Improving quality of life with people living with chronic diseases*, aiming to reach better understanding about what it will take to reverse the trends and slow the rise of chronic diseases in Europe and how can governments support patients and ensure the best possible quality of care and life. The event attended by **Policy Officer Lana Crnjac** started with an interview of **Vytenis Andriukaitis, European Commissioner for Health and Food Safety**, who repeated that we lack of strong political will on national levels to improve management of chronic diseases.

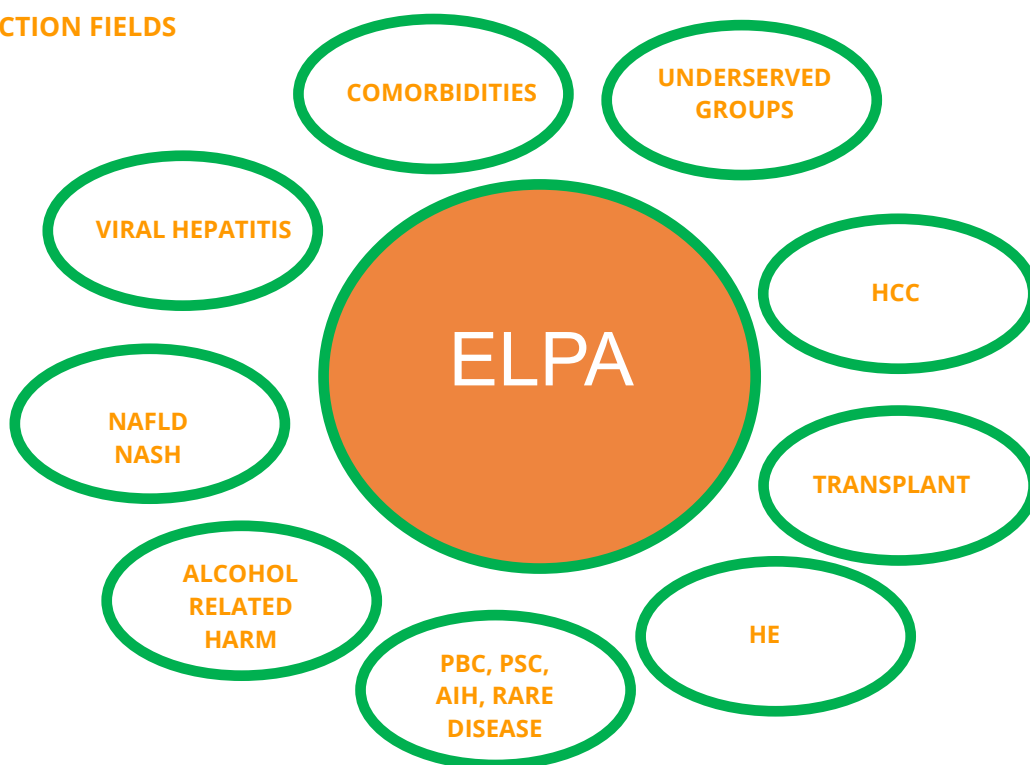
PBC network advocacy meeting

With the first one held in December 2016 in Frankfurt, PBC network held the second PAN-EU PBC advocacy meeting on March 2nd in Amsterdam, where several ELPA members were present (HAA, EpaC, The Finish Kidney and Liver Association, PBC Foundation and Leverforeningen Denmark). ELPA itself was represented by President **Tatjana Reic**. The purpose of the meeting was to agree on the goals and smart objectives of the network, learn more about the experience of the stakeholders included, discuss how the network can be managed and, finally, prepare for the meeting/s during 52nd EASL ILC in Amsterdam.

HCV Elimination Mini Policy Summit “Eliminating HCV in Romania

On 27th of November Tatjana Reic, **as ACHEIVE chair and ELPA President**, took part in Mini Policy Summit “**Eliminating HCV in Romania**”, organized by Hepatitis B and C Public Policy Association and hosted by **MEP Cristian Silviu Buşoi**. This event aimed to bring together policy makers, patient representatives, academics, clinicians and industry from Romania and EU level, who will later leave the Summit with a stronger commitment to work jointly towards the elimination of HCV and a clearer understanding what could and should be done to eliminate HCV in Romania and how the EU could support this effort. **Marinela Debu**, ELPA Vice President also delivered a presentation on this occasion.

ACTION FIELDS



Launch of documentary film „From Hell to Hope

Going further in raising the awareness on Hepatitis C and consequences that it has both on patients and their families, in collaboration with AbbVie and Proddigi film, we have made a documentary movie showing the struggle of the people who were once diagnosed, are still fighting or are helping to eliminate this disease. The movie was launched as a pre-EASL activity and was showed on ELPA booth during the ILC. You can watch the full movie <http://www.hcv-doc.com/>

Moscow conference ahead of the World Hepatitis Day

Russian team from *United against Hepatitis* organized a press conference on 25th of July, to mark this year's World Hepatitis Day. ELPA President Tatjana Reic was asked to participate and support

this raising awareness conference via Skype, joining so Antons Mozalevskis from WHO and Charles Gore from WHA. The goals and objectives of the conference were to draw attention to the situation with hepatitis, to discuss issues related to hepatitis as well as their solutions, to highlight the importance of raising awareness of transmission and many more.

ELPA is continuing to improve the management of Hepatic Encephalopathy

ELPA have launched a patient leaflet to improve the early detection of hepatic detection of hepatic encephalopathy, and a patient passport to facilitate conversations with healthcare professionals. Hepatic encephalopathy remains under-diagnosed and under-treated, as many patients and carers are unaware of the signs and symptoms of the disease. In addition, healthcare providers don't always identify and treat the often subtle symptoms of hepatic encephalopathy, and this can lead to poor patient outcomes and increased hospital admissions.

Hepatic encephalopathy is a significant complication of advanced chronic liver disease, and occurs in up to 40% of patients or as many as 200,000* people in Europe. All the materials were produced in line with our successful Time To Deliver Campaign.

NASH: GAIN 1st Expert Review Group Meeting

ELPA President **Tatjana Reic** and Scientific Team leader **Ingo Van Thiel** represented ELPA in 1st Expert Review Group meeting as patient representatives. This side meeting during AASLD's LM 2018 was organized by HCD Economics, which leads an observational study on NASH on behalf of the University of Chester. The purpose of the study is to investigate the burden of illness associated with NASH in adult patients in Europe and in the United States in a real-world setting.

PBC International Day 2017

PBC International Day 2017 was marked by a joint campaign, carried out by advocacy organizations working in the field of rare diseases, liver disease or PBC. The aim of this campaign, which was devised by **PBC Network** and led by ELPA member **Nederlandse Leverpatiënten Vereniging (NLV)**, was to heighten awareness and bring attention to this auto-immune disease. This campaign was implemented and carried out worldwide, especially Europe where ELPA plays a major role in patients advocacy.

PBC is a rare disease that affects 1 person in 100,000¹

9:1 female-to-male ratio²

Most common in women aged 40+¹

Treatments are available to slow disease progression and manage symptoms

Liver transplantation is used for those with end-stage liver disease¹

Feelings of isolation and loneliness are common side effects of the condition³

Sharing experiences and connecting with others can help³

#PBCandMe

SUNDAY 10 SEPTEMBER

international PBC day 2017

#PBCandMe

PBC Day goes global

Hepatitis Hilfe Österreich
Hepatitis Hilfe Österreich shared three GIFs on their Facebook page

The Finnish Kidney and Liver Association
Infographic translated to Finnish and shared on The Finnish Kidney and Liver Association's Facebook page

Rarissimas Portugal
Rarissimas translated all the infographics into Portuguese and shared on their Facebook page

NLV (Nederlandse Leverpatiënten Vereniging)
NLV posted 15 tweets with a reach of 17.3K including four GIFs in the run up to PBC day

ELPA
ELPA posted 26 tweets reaching over 100,000 followers. On PBC Day a video of ELPA's President, Tatjana Reic discussing PBC was shared and re-shared by key opinion leader Jeffrey V. Lazarus who has 4,802 followers

PBC Sverige
PBC Sverige translated one of the infographics into Swedish and posted it on their Facebook page

Liver4Life
Liver4Life shared two tweets with reaching over 3,000 liver experts and advocates in the UK

American Liver Foundation
American Liver Foundation set up a fundraising page on their Facebook. So far they have raised \$361 beating their target of \$200

PBC Foundation
PBC Foundation posted five tweets with a reach of 8,840

Canadian PBC Society
The Canadian PBC Society posted a series of five 'letters' on Facebook raising the awareness of PBC and its symptoms

Canadian Liver Foundation
The Canadian Liver Foundation shared two GIFs on Twitter and invited individuals to share their stories using #PBCandMe

SLAP - Save Liver Association for Patients
Save Liver Association for Patients shared the PBC day logo on their Facebook page

PBCers
The PBCers hosted a lunch with patients and patient organisations and shared a photo using the hashtag #PBCandMe on Twitter

Forening for autoimmune leversykdommer (FAL)
Forening for autoimmune leversykdommer translated the factsheet into Norwegian

EPAC Italia
EPAC translated the press release and shared with journalists in Italy and it was published in a local newspaper PharmaStar

Leberhilfe Projekt gUG
Leberhilfe Projekt completed a survey around PBC GoL and management and presented the results at the national congress of gastroenterologists. They also developed an online platform for people living with PBC in Germany

SUNDAY 10 SEPTEMBER

international PBC day 2017

Alcohol related harm activities

Promoting the interests of people with liver disease in Europe, European Liver Patients' Association strongly highlights the risk of excessive alcohol intake and the consequences that it has, inevitably leading to alcoholic liver disease.

When a person drinks alcohol heavily over the course of decades, the body starts to replace the liver's healthy tissue with scar tissue. This condition is called alcoholic liver cirrhosis and can lead to liver cancer. Unfortunately, not everyone is fully aware of the harm caused by alcohol intake and all of the consequences it has to their body. As ELPA President Tatjana Reic commented: *Alcohol has many health risks and excessive drinking causes damage to many areas of the body, especially the liver. The more people cut down their levels of alcohol consumption, the more they cut their risk of cancer.* Liver patients' often face stigma related to any kind of liver disease, in particular diseases caused by alcohol intake. That often hinders the process of admitting the problem and therefore treating it on time. For all the reasons mentioned above, in 2017 ELPA has continuously worked on alcohol related advocacy activities such as alcohol labelling initiative and, traditionally, AWAHR week, organized by Eurocare. As a response to non satisfactory European Commission's published report on alcohol labelling, stakeholders organized in order to exchange ideas and to consider the possibilities for cooperation. Later on in the year, AWAHR week was traditionally marked by a meeting in European Parliament and , the Health Attaché breakfast meeting.

ELPA in EU funded projects

HA-REACT meeting on financing of harm reduction service

Just at the beginning of April, ELPA President **Tatjana Reic** attended HA-REACT meeting on financing of harm reduction services. This initial planning and experience sharing meeting later on served as an important milestone in coordinating efforts to improve the funding and sustainability of harm reduction services. This meeting was intended to be a kick-off event for a series of meetings and publications that the Joint Action will organize in future.



Launch of INTEGRATE project: EU-funded Joint Action

On 19th of September ELPA has participated in the afternoon a policy session and debate on how to move towards integration of HIV, hepatitis, TB & STIs was arranged with the official launch of the EU-co –financed Joint Action on integrating prevention, testing and link to care strategies across HIV, viral hepatitis, TB and STIs in Europe (INTEGRATE), which brings together 29 partners from 15 countries. INTEGRATE is funded by the 3rd EU Health Programme and will run over three years (September 2017-August 2020). 29 partners have been nominated by their Ministry of Health, representing 15 EU countries plus Serbia. Partners are Public Health institutions, Hospitals (infectious disease and research departments), NGOs and Universities. Furthermore, ELPA was asked to be **part of Advisory Board**, which President Tatjana Reic kindly accepted. Launch was followed by series of workshops, held on 20th in the premises of DG Sante, where Commissioner Andriukaitis addressed all the participants. During this event ELPA was represented by **ELPA President Tatjana Reic** and **Policy Officer Lana Crnjac**.

Research programs

Project Galaxy

Project GALAXY, where ELPA is one of the consortium partners, is moving forward. As part of the activities, **Tatjana Reic**, **Marko Korenjak**, **Livia Alimena** and **Lana Crnjac** had a meeting with their research team in April in Amsterdam.

Project Liverhope

LIVERHOPE IS EU FUNDED PROJECT AIMING TO INTRODUCE SIMVASTATIN AND RIFAXIMIN AS NEW THERAPY FOR PATIENTS WITH DECOMPENSATED CIRRHOSIS.

Liver cirrhosis represents the end-stage of a chronic disorder which results in severe and permanent damage of a vital organ. In recent years, liver cirrhosis was one of the leading causes of death in adults worldwide, both in males and females. The number of deaths due to cirrhosis in Europe has been estimated to be around 170,000 annually, with varying mortality rates in different European countries.

On January 12th we took part in **Liverhope** kick-off meeting in Barcelona, during which **Marko Korenjak** ELPA Vice President, presented ELPA and patients' view on the project, receiving a very good feedback from all the assembled professionals working on **Liverhope** project. Essential topics discussed during the meeting include: project overview, economic reporting, monitoring issues and dissemination of the results.

Furthermore, for the next five years, which is the whole duration of the project, ELPA will act as a key point in dissemination of results and all other information regarding the project.

Project Liverscreen

Project LIVERSCREEN, where ELPA is one of the partners, has successfully passed the first stage in 2017 (submission of all the documents and a review by Commission). As the next step was professional hearing, **Marko Korenjak**, ELPA Governing Board Member, travelled to Munich on June 12th and participated in it as one of only four members invited.

III Strengthening our organization



Launch of ELPA working groups

As announced in ELPA Strategy for 2017, describing Strategic goal 1 *Members empowerment, Action 1.2*, ELPA has started establishing its first working groups. The groups such as Rare diseases group and Hepatitis B group will gather experts and ELPA members to work together on group related specific issues.

ELPA meetings in Palermo

After months of preparations, ELPA Team building, **ELPA Stakeholders' meeting** and **Advisory Board Meeting** took place in Palermo from November 26-29. As a set of annual ELPA meetings, this period represented a great opportunity for ELPA members to meet on a one day meeting, which included both team building exercises and later discussion on ELPA activities through which the members could've shared their thoughts with the Board members. This was followed by Stakeholders' meeting on 27th when ELPA outlined plans for activities to be carried out in the upcoming 2018.

Several Stakeholders' representatives shared their plans and have contributed to the fruitful discussion, including **European Commission** represented by **Jean-Luc Sion**, **Prof. Dr. Rui Marinho Tato** representing **International Symposium on Hepatitis Care in Substance Users (INHSU)**, **Eberhard Schatz** from **Correlation Network**, **Greet Hendricx** from **VHPB** and **Prof. dr. Ammal Mokhtar** and **Ivana Dragojević**, Board members of **World Hepatitis Alliance (WHA)**.

Visiting Ukrainian member NGO Stop Hepatitis and attending ECAB meeting

ELPA President, **Tatjana Reic** and **Dmytro Koval** represented ELPA on ECAB meeting on viral hepatitis from 8 to 10 December. Apart from attending meetings with Gilead and MSD, ELPA President was delighted to be able to hold a fruitful meeting with one of the ELPA's members, **NGO Stop Hepatitis**, in their hometown.

During the stay in Kyiv she has also met with **Prof. Olha Golubovska**, main hepatitis expert in Ukraine, to discuss the specific situation in the country. After the meeting, it was concluded that, due to a sensitive political situation in the country, the elimination plan and the strategy might be jeopardized.

During the second day of the ECAB meeting on viral hepatitis, training for 25 participants from various organizations from Eastern Europe and Central Asia took place.

Communication

Post of the month

 **ELPA**
@HepatitisEurope Following

EU Commissioner for Health & Food Safety @V_Andriukaitis and Vice president of #ELPA send a strong message #NOhep for the new generations Universal Health Coverage for all #Access2030 #elimination2030 in Europe for #HCV at @EUparl together we are stronger @EU_Health @WHO_Europe



Our post of the month has to go to ELPA who posted a picture on Twitter of ELPA Vice President Milan Mishkovikj alongside European Health and Food Safety Commissioner Vytenis Andriukaitis. Visibility is a core focus of the NOhep movement to ensure everyone living with hepatitis is recognised and has a voice. We're delighted to see Vytenis Andriukaitis supporting NOhep and hope to see many politicians and policymakers follow his lead.





ELPA's presence at Social Media Channels

What kind of Benefits ELPA and its members have from social media networks?

Promoting the activities, sharing information, dissemination of polls, event announcement, lobbying, raising awareness, education, influencing, mentions, analytics, impressions, transparency, sharing ideas, making networks, toolkits, key messages, likes, target groups, questions, tagging influence people and organizations ... through social media helps us being heard even more and to achieve our goals.



Twitter 4,297 Followers
Facebook 3,630 likes & followers
In 2017 more than 10 million people visit us on social media



Over the 2017, ELPA has been communicating both externally and internally through its communications channels on a daily basis. Wanting to keep our members updated, we have been sending out weekly activities reports, which are sent to every ELPA member. Apart from ELPA website and these weekly reports, more detailed description of our activities are published four times a year as Quartal News Reports, which can also be found on ELPA website.

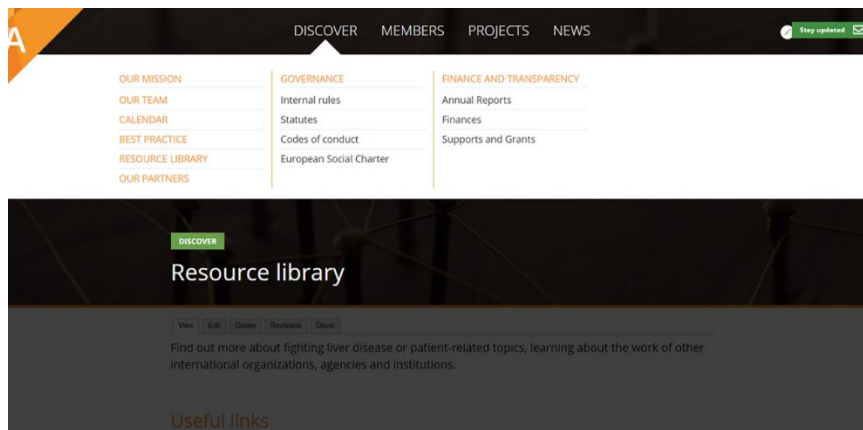


ELPA Interviews viral hepatitis stakeholders



From www.elpa-info.org to www.elpa.eu





Following the change of ELPA logo sign, first mid of April was marked by the launch of new ELPA website www.elpa.eu, as well as of transfer to new e-mail addresses (name.surname@elpa.eu). As a continuation to our domain change from elpa-info.org to elpa.eu, ELPA team has changed their e-mail addresses, which you can also add to your address book.

Below please find the list of new addresses:

Tatjana Reic, President: elpa-president@elpa.eu; tatjana.reic@elpa.eu

Marinela Debu, Vice president/Treasurer: marinela.debu@elpa.eu

Angelika Widhalm, Vice president: angelika.widhalm@elpa.eu

Milan Mishkovikj, Vice president: milan.mishkovikj@elpa.eu

Marko Korenjak, Vice president: marko.korenjak@elpa.eu

Lana Crnjac, Policy Officer: office@elpa.eu

Ingo Van Thiel, Scientific Committee Leader: ingo.vanthiel@elpa.eu

ELPA GOVERNING BOARD

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.

Tatjana Reic, President
Marinela Debu, Vice President
Angelika Widhalm, Vice President
Robert Mitchell-Thain, Vice President
Milan Mishkovikj, Vice President
Marko Korenjak, Vice President

SCIENTIFIC COMMITTEE

Ingo van Thiel, Scientific Committee Leader
Teresa Casanovas
Marco Bartoli
Robert Mitchell-Thain

ELPA SECRETARIAT

Livia Alimena, Public Affairs Director
Lana Crnjac, Policy Officer
Nathalie Krone-Seywald, Event Manager
Veronika Vsetickova, ELPA Administrator

FINANCIAL ACCOUNTING AND TRANSPARENCY

ELPA accounts are finalised in time for approval at the Annual General Meeting. The 2016 final accounts will be available in April 2016 and are therefore not included in this report. Full information will be posted online at www.elpa.eu.

AKNOWLEDGEMENTS

ELPA is thankful to all its members and numerous volunteers that have helped us accomplish our goals in 2016. We are also thankful to all our stakeholders who have been supporting our endeavours in fighting the liver diseases over the years.

In 2017 ELPA received grants as well as, in some cases, in-kind support, from the following companies:



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