

ELPA

Quartal News Report

October – December 2017

Communicable Diseases Summit in Vilnius

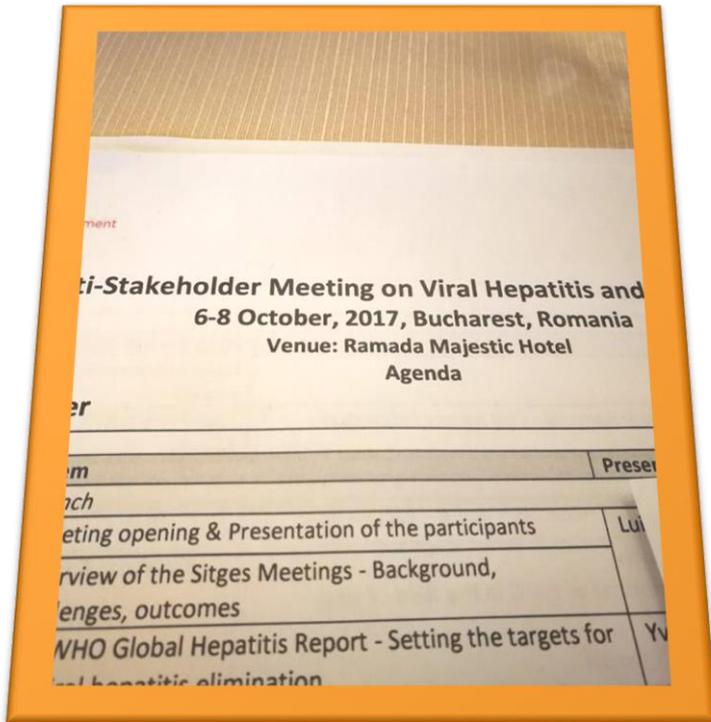
- **ELPA President Tatjana Reic** participated in the second **Communicable Diseases Summit in Vilnius**, where she held a key lecture on ACHIEVE coalition, presenting coalition's objectives and work that has been done so far.
- Paralel with the Summit in Villnius, European Haemophilia Consortium have 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 microelimanation ELPA and EASL joint workshop at ILC 2018 in Paris.

Goals of this workshop should be :

focusing on viral hepatitis micro elimination targeting comorbidities like haemophilia, thalassemia, and PWIDs, dialysis patients, migrants, infants, MSM and prisoners; mapping the epidemiology through registries within those groups; surveillance of treatment outcome and involving ECDC, EU Commission, ELPA, WHA, WHO EU, Haemophilia Consortium, TIF, ESTA/ERA, UNHRC, EASL, EILF.

EATG 10th Multi Stakeholder meeting

Marko Korenjak, ELPA Vice President, 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.



ELPA at World Health Summit



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**.

High Patrons of the World Health Summit



Angela Merkel, Chancellor of the Federal Republic of Germany (c)
Bundesregierung / S. Kugler



Emmanuel Macron, President of the Republic of France



Jean-Claude Juncker, President of the European Commission

NASH meeting by Global Liver Institute

Prior to the AASLD's Liver meeting, **Marko Korenjak** took part in Global Liver Institute's (GLI) NASH meeting, held on 18 - 20 October in Washington. There he has met dozen important USA NASH/NAFLD stakeholders - doctors, patient representatives and industry, with whom he was able to share ELPA's activities and work done on NASH problematics concerning patients so far. On that occasion the leadership of Global Liver Institute embraced collaboration with ELPA and invited ELPA to join their Council, to which ELPA team is looking forward to.

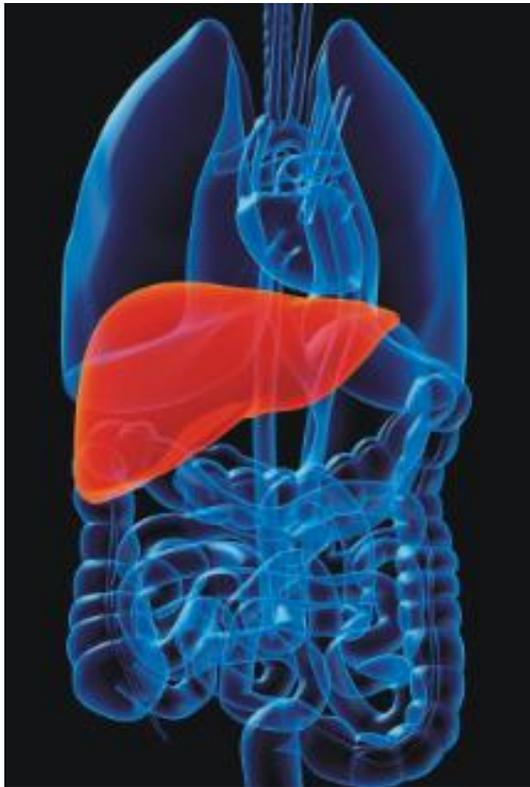


ELPA at The Liver Meeting 2017

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. This year's The 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.



NASH: GAIN 1st Expert Review Group Meeting



ELPA President **Tatjana Reic** and Scientific Team leader **Ingo Von 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.

Pre-Summit members' Conference in Sao Paulo

Just before the official start of the **World Hepatitis Summit**, members of World Hepatitis Alliance had a **Pre-Summit member conference** 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.



World Hepatitis Summit 2017

From 1st to 3rd of November hepatitis community gathered in Sao Paulo 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.



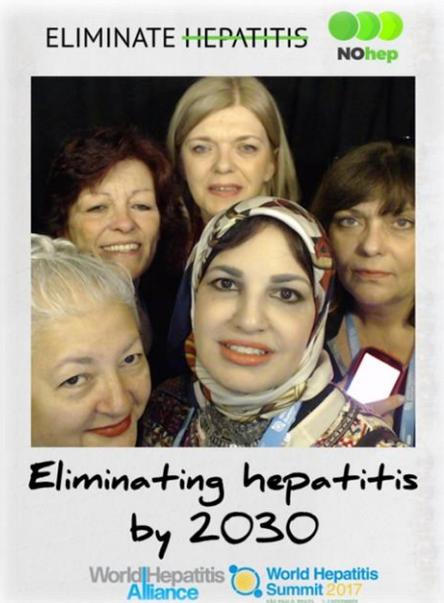
World Hepatitis Summit 2017 - continue

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.





Representing European liver patients, ELPA attended the Summit, engaging in the meetings as well as the side meetings. During the Summit ELPA representatives took the opportunity to hold meetings with other stakeholders and industry representatives, but also to spend some time together and networking.





ELPA representatives have held short interviews with **Gottfried Hirnschall**, Director of the HIV/AIDS Department and the Global Hepatitis Programme (GHP) at WHO, **Marc Bulterys** (GHP Team Leader), **Antons Mozalewskis** (WHO EURO), **John Ward** (CDC), **Homie Razavi** (CDA), **Charles Gore** and **Michael Ninburg** (WHA). This series of interviews, through which ELPA wants to empower its membership conveying messages by some of the prominent world leaders in the elimination of hepatitis, will be presented on ELPA website.



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 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**.

Meeting with Cristian - Silviu Busoi MEP

On November 8th ELPA President **Tatjana Reic** and Policy Officer **Lana Crnjac** 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.



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**.

Launching Hep-CORE 2017 preliminary results



Hep-CORE first patient led study preliminary results 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, **Katrin Schiffer** from Correlation Network presented their work and underlined the usefulness of the Hep-CORE study as ELPA stakeholders. During the presentation participants could have heard three best practice stories from Italy and Portugal, presented by: **Emilia Rodriguez & Luis Mendao**, **Marco Bartoli**, and **Milan Mishkovikj**. Official presentation of the results from 2017 will be held in the first quarter of 2018.



More Trust, More Data, Better Health

Policy Officer **Lana Crnjac** attended meeting on data, ethics and innovation in health in European Parliament. The meeting took place on 7th of November and was 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. To examine whether enough is being done and what challenges may still lie ahead, Microsoft organised this meeting as a launch of their one-year roadshow.



ELPA@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.



AWARH 2017: alcohol and cancer

A meeting in European Parliament was held on 23rd of November and was hosted by **Dr Biljana Borzan**. Just after the discussion in EP, the Health Attaché breakfast meeting was organized on 24th where Health Attachés from Member countries had the opportunity to hear presentations delivered by WHO and UEG, as well as EUROCARE's views on alcohol related policies in Europe. On both of the events ELPA was represented by Policy Officer **Lana Crnjac**. As the partner in this alcohol harm raising awareness week, ELPA has sent out an important message on patients' view, published in AWARH newsletter.

In its 5th year, **the European Awareness Week on Alcohol Related Harm (AWARH)** took place from 20th – 24th November 2017, with various activities being carried out under the theme of "Alcohol and Cancer". Research in Europe has shown that 1 in 10 Europeans do not know about the connection between alcohol and cancer, and that 1 in 5 do not believe that there is a link between cancer and the drinks.

As a part of AWARH week that is organized annually by **EUROCARE** and other AWARH partners, including ELPA.



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)**.





Palermo meetings were closed with 2,5 day long community Advisory Board meeting that was taking place on 28th and 29th, giving ELPA members the opportunity to hear the updates from medical teams representatives of **Abbive, BMS, Genfit, Gilead, Intercept, Janssen, MSD, Norgine and Novartis**. Prior to the start of Stakeholders' meeting and ABM, ELPA Board has met and held Board meeting.

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 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.



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.

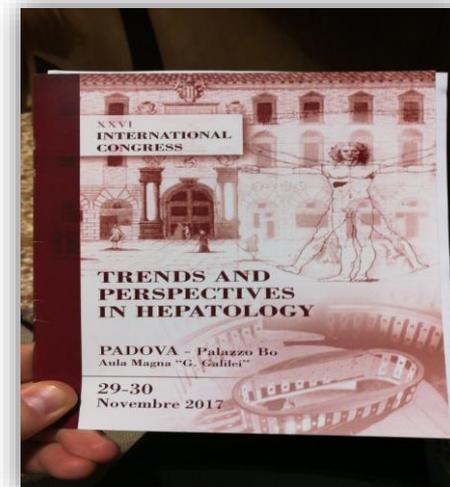


"Trends and perspectives in Hepatology"



After international congress ELPA, represented by Vice President **Marko Korenjak**, was invited in the University hospital in Padova. After short review of the work with liver patients under the director **prof. dr. Paolo Angeli**, they have also visited patients that agreed on being part of the EU Horizon2020 project LIVERHOPE. Another visit was also made to the special laboratory in the hospital where more attention was given to the sleeping laboratory that is ran by **Prof. Dr. Sara Montagnese**. The sleeping laboratory is one of the few in the world that is focusing on sleeping disorders that patients with liver cancer experience on regular basis.

ELPA was part of International congress in hepatology in University of Padova on 29 and 30 of November. The international congress "Trends and perspectives in Hepatology" included Vice President of ELPA **Marko Korenjak** presenting "**What is ELPA expecting from and doing for hepatology: the strategy of patient communication.**" The invitation to present came from **Prof. Dr. Paolo Angeli**, who was hosting the conference.



ELPA@home workshop and Stakeholders meeting in Poland

An amazing finish of the ELPA@home program for 2017! Poland was the final country 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 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.

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 Vice-President **Milan Mishkovikj** asked few questions to Mr. **Vytenis Andriukaitis**, **EU Commissioner for health and food safety**, which you can find below, together with Commissioner's answers.

• ***What are the next steps of the European Commission regarding the issue of Hepatitis as a public health threat in the European Union and the European region?***

„The European Commission will make recommendations on how the countries, which are still not members of the EU, can send country-specific reports of the situation in their countries when hepatitis is concerned."

• ***Do the refugees represent a threat regarding infectious diseases?*** "The European Commission's position is that refugees do not pose a threat, but they think that a careful policy on this issue should be taken".

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.





Kyiv, Ukraine ECAB meeting and visiting ELPA member *NGO Stop Hepatitis*

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. Olga 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.





EU HIV/AIDS, Hepatitis and Tuberculosis Civil Society Forum 2017

ELPA President, **Tatjana Reic** represented ELPA on the renewed and extended **EU HIV/AIDS, Hepatitis and Tuberculosis Civil Society Forum** which took place from 18 until 19. 2017 in Luxembourg.

On the first day, **December 18th**, one of the main aims of the meeting was to agree on the new CSF governance structure and strategy and to identify working priorities for the upcoming period and how the CSF can feed into the work of the Commission, the upcoming Presidencies, EP elections and represented agencies: WHO, ECDC, UNAIDS.

ELPA President, **Tatjana Reic**, had presented the Achieve Coalition and the Coalition to Eliminate Hep B while the ELPA project Hep- Core was presented by Prof. **Jeffery Lazarus**.

During the day two of the Forum, the continuation of CSF meeting it was concluded that the first on the agenda now is the contribution to the staff working document, prepared by **Jean Luc Sion** with contributions and review by his colleagues in other DG's at the Commission. The staff document is not a political document, but will highlight the current status ' where are we' and 'what is still needed', based on the efforts the Commission did in the past. In January, CSF will have the opportunity to comment and to suggest changes.

Hep-CORE 2018 preparations



ELPA President, **Tatjana Reic**, **Prof. Jeffrey V. Lazarus** and **Lana Crnjac**, ELPA Policy Officer had a constructive meeting on **December 20th**, in Luxembourg, regarding new methodology that will be used for future development of **Hep-CORE** study in 2018. They are developing a strategy for the official launch of results from the report as well as a timeline for this year.

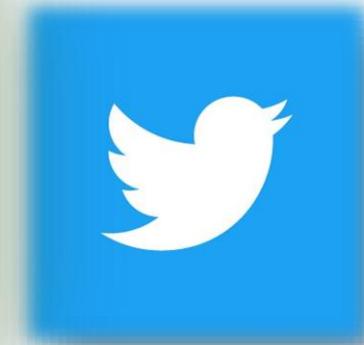
ELPA's presence at Social Media Channels

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



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; to share experience of successful initiatives; to work with professional bodies such as EASL and with the EU to ensure that treatment and care are harmonized across Europe to the highest standards.

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