

Leaving a trace.
ELPA Annual Report
2016

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 35 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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#LiveREurope

LETTER OF THE PRESIDENT



Tatjana Reic, President of ELPA

Dear ELPA shareholder,

For the last 12 years, ELPA has been untiringly leading the way in advocating for liver patients' rights. Since its beginnings ELPA members, executives and supporters have been working together and leaving a trace with each and every activity designed to put the patients in the forefront. I am proud to say that 2016, as well as its predecessors, was a year of endeavours in assuring further healthcare improvements for all liver patients and of various projects dealt with success. So far we have built a strong network through which we can carve out significant victories in the field of viral hepatitis and other liver diseases, but only if we go on supporting each other, exchanging the experience we have gained and continuing, without ceasing, to acquire comprehensible knowledge. 2016 has been a year of dedicated work through which our diligent team has contributed in many initiatives, having in mind all the time that only by mutual cooperation we can achieve our goals. From here, we go further, more decisively and with the same audacity in bringing about the changes for patients and their families. In 2017, it will be both my duty and honour, as the President, to grow ELPA's platform even stronger and to facilitate partnerships that will bring us tangible results. I invite you to join me on that journey during which we will overcome the obstacles and celebrate the fruits of our commitment together. Notwithstanding the world without liver diseases is still a distant dream, we should remind ourselves of our accomplishments and of myriad positive stories which serve us as the wind at our back.

Tatjana Reic, President

CONTENTS

OUR MISSION	2
LETTER OF THE PRESIDENT	3
ELPA MEMBERS IN 2016	5
SHORT PREVIEW	6
2016 ELPA HIGHLIGHTS	8
<hr/>	
ELPA at International Liver Congress 2016	8
ELPA Symposium: New HCV DAAs: Is Universal Access still a Dream?	10
Meeting Mr. Vytenis Andriukaitis, European Commissioner for Health and Food Safety	11
Hep-CORE study	12
ELPA University	17
<hr/>	
2016 HEPATITIS BREAKTHROUGHS	21
<hr/>	
WHO's aim to eliminate viral hepatitis by 2030	21
Adoption of European Action Plan	22
<hr/>	
ADVOCACY AND ENGAGEMENT WITH STAKEHOLDERS	25
WORKSHOPS AND TRAININGS	35
LOOK INTO THE FUTURE	36
ELPA GOVERNING BOARD AND SECRETARIAT	36
FINANCIAL ACCOUNTING AND TRANSPARENCY	37
ACKNOWLEDGEMENTS	37
GET IN TOUCH WITH US	40

ELPA MEMBERS IN 2016

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)
EGYPT	Association of Liver Patients' Care (ALPC)
FINLAND	The Finnish Kidney and Liver Association
FRANCE	SOS hépatites Fédération
GERMANY	Deutsche Leberhilfe e.V. Deutsches Hepatitis C Forum 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
LITHUANIA	Infectious Diseases Patients Association (LIDPA)
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

SHORT PREVIEW

2016 AT A GLANCE



100 000 More than 100 000 individuals reached within ELPA network

3,534 Twitter followers

1,710 Facebook fans

51 More than 50 activities conducted by ELPA or in collaboration with stakeholders

35 Members

27 Countries

8 Governing Board Meetings

6 Major events

1 Hep-CORE study

January

1. Meeting Mr. Vytenis Andriukaitis, European Commissioner for Health and Food Safety
2. HA-REACT joint action kick-off meeting

February

3. APASL 2016: Viral Hepatitis Policy Symposium
4. WHO workshop: Better Food for Better Health
5. HCV EU Policy Summit: Hepatitis C: The Beginning of the End

March

6. HCV 2020 Forum 2016: accelerating action
7. Viral Hepatitis Prevention Board meeting in Ljubljana
8. Enhancing Value in European Health Systems: Improving Outcome
9. Kangaroo Group panel debate
10. European Patient Forum (EPF) - Annual General Assembly
11. Recruiting patients for clinical trial

April

12. WHO Europe advisory committee for the EU Action Plan for the prevention and control of HIV/AIDS and Viral Hepatitis
13. ELPA Strategy Workshop
14. ELPA at International Liver Congress (ILC 2016) of the European Association for the Study of the Liver (EASL).
15. ELPA Symposium: New HCV DAAs: Is Universal Access still a Dream?
16. Regional HCV Launch
17. ELPA at Civil Society Forum 2016

May

18. FibroScan Compact 530 donation to Zagreb Hospital
19. ELPA University combined module 4 for year one and module one for year two
20. WHO – 69th World Health Assembly

June

21. Hepatitis C Italian national congress on access to treatments promoted by EpaC

July

22. Exploratory meeting on a joint stakeholder initiative on HCV
23. World Hepatitis Day 2016

August

24. HCV Patients' protest in Bulgaria
25. Administrative work and preparations for fall

September

26. Project PBC Educational day
27. ELPA University IMPACT Programme
28. Women in High Places: Leading the Global Challenge of Hepatitis and Liver Cancer Control
29. RC66 meeting of WHO EURO region
30. The roadmap for cure: AASLD – EASL special conference
31. WHO Regional Technical Consultation in Minsk

October

32. Second exploratory stakeholders' meeting on viral hepatitis elimination
33. Call to Action to improve Organ Donation and Transplantation across the EU
34. Georgian HCV Elimination program, second TAG meeting
35. Viral Hepatitis Prevention Board: Country Meeting in Albania

November

36. HA-REACT 2nd Advisory Board meeting
37. Nordic Groups Meeting
38. The Liver Meeting 2016
39. AWARH campaign 2016 and Health Attaché breakfast meeting
40. WHA Regional Board Member elections Second meeting with Mr. Vytenis Andriukaitis,
41. European Commissioner for Health and Food Safety
42. EMA trainings in London
43. Finland adopting Hepatitis C strategy for 2017-2019

December

44. ELPA University Impact Programme year 2 module 3
45. Advisory Board Meeting in Warsaw
46. ELPA's participation at EATG's Policy Meeting on Access to DAAs in EECA
47. PBC PAN EURO Advisory Board
48. ELPA Stakeholders' meeting
49. International press conference in Berlin: Hep-CORE Report Launch

2016 **ELPA HIGHLIGHTS**

PHOTO ESSAY

ELPA at International Liver Congress 2016



Tatjana Reic, President of ELPA at ILC opening session, Barcelona



ELPA President accepting the donation in Barcelona

Annual International Liver Congress of the European Association for the Study of the Liver was held in Barcelona from 11th to 17th April. ELPA President, Board and all members took part in the congress and some other activities such as ELPA's Annual General Meeting, training day, workshops and meetings like *Transforming HCV Care Together. Management of Hepatic Encephalopathy: A serious neuropsychiatric complication of advanced Chronic Liver Disease* and *Eliminating hepatitis C – making it real*.

During the opening ceremony of the ILC, ELPA President **Tatjana Reic** was honoured to address more than 10.000 congress participants at the Opening session. That was a great opportunity to underline that the fight for political recognition of the fight against the viral hepatitis is not over yet: *„The European Commission struggles internally to adopt an EU Policy Framework on HIV, Hepatitis and TB, which has been envisaged for quite some time now, but where little progress appears to be made. To me, it is clear that the European Commission needs our help. We need to demonstrate consensus on what is needed to eliminate Hepatitis at European, national and local level. Policymakers, public health experts, healthcare professionals and patients need to come together to look at primary and secondary prevention, access and prevention of re infection, and to develop strategies on how to best approach the different risk groups. As for the global level, we need a UN Declaration on Hepatitis. The fact that there are currently discussions on updating the Dublin Declaration on HIV should make us think – why not include Hepatitis, as well as TB? Each of these diseases should be included in their own right in an updated Dublin Declaration. Generally, the future is in exploiting synergies wherever possible. We need to be clever and also investigate how we can exploit synergies between prevention, diagnosis, and management of other diseases to optimize health systems outcomes. Chronic diseases, including chronic liver diseases, are diagnosed far too late, and primary care is underutilised for both prevention and diagnosis. Non-alcoholic fatty liver disease – NASH - is a case in point here. The problem is that primary care professionals frequently do not have the right tools available. Health check-ups frequently do not include liver enzyme tests, and healthcare professionals are usually not rewarded for an early and correct diagnosis – in fact, just on the contrary.”* In her speech, the President concluded that a lot has been achieved in terms of therapy, but a lot more needs to be done to reduce the burden of liver disease.

After the opening session and in the days to follow, ELPA President **Tatjana Reic** and Public Affairs Director **Livia Alimena** had several successful stakeholder meetings with EASL governing board, industry, clinicians and nurses as well as

international organisations' representatives for European projects such as Galaxy and our project Hep-CORE. Our Board member **Robert Mitchell-Thain**, presented his winning project Improve PBC care: *Practice to Policy applications and their corresponding PBC initiatives* while prof. **Jeffrey V. Lazarus** (University of Copenhagen) and ELPA Special policy consultant, **Achim Kautz**, announced to the audience the **Hep-CORE project**, a study documenting how ELPA member countries are addressing hepatitis B virus (HBV) and hepatitis C virus (HCV) prevention and treatment today.

ELPA Symposium: New HCV DAAs: Is Universal Access still a Dream?



Fighting hepatitis stakeholders on ELPA Symposium in Barcelona

During the International Liver Congress, ELPA's, now traditional, symposium took place and was co-chaired by ELPA Vice President **Ivan Gardini** and **Charles Gore** (WHA). Under the title *New HCV DAAs: Is the universal access still a Dream?* the symposium gathered together international experts (spanning from Europe to USA, from Australia to Africa) and KOLs on Hepatitis who focused on its epidemiology (130 to 150 million people living with chronic hepatitis C), and analysed the new treatments which can also cure people with advanced cirrhosis, HIV coinfection and other severe comorbidities. On this occasion, we wanted to look at the big picture: how does the access work across different continents? What has been improved since 2014? Which solutions work, which barriers are still in place? What are the best practices we could learn from? During the Symposium, Ms. Gjulten Abdullai, a patient from Macedonia, shared her story in front of the audience and has been finally granted the treatment thanks to **Ivan Gardini** (EpaC President) together with Professor **Antonio Craxi** MD, Head of Dept. of Internal Medicine and Medical Specialities University of Palermo (Italy).

PHOTO ESSAY**Meeting Mr. Vytenis Andriukaitis, European Commissioner for Health and Food Safety**

*From the left:
Tatjana Reic,
Commissioner Vytenis
Andriukaitis and
Ivan Gardini*



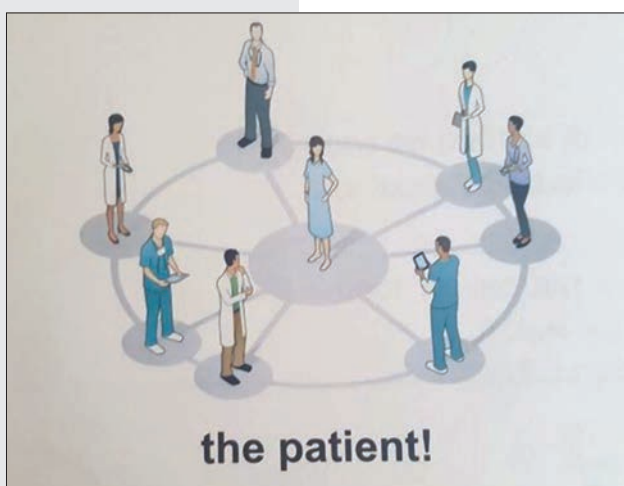
Joint stakeholders' meeting with Commissioner

One of 2016 advocacy work highlights were two meetings held with the European Commissioner for Health and Food Safety, **Vytenis Andriukaitis**. Immediately at the onset of the year **Tatjana Reic** and **Ivan Gardini** managed to set the first meeting with the Commissioner to discuss future EU policies regarding viral hepatitis, as well as the one on alcohol related harm. The Commissioner recognized the opportunity to eliminate Viral Hepatitis and discussed possible strategies to be adopted within the limits of EU competence. Later in November group of stakeholders, together with ELPA, participated in the second meeting with the Commissioner, advocating again for EU commitment on Viral Hepatitis. The meeting was dedicated to the very much needed integrated plan which would fit the objectives of the EU Health Programme. Just during that meeting ELPA's President **Tatjana Reic**, representative of Viral hepatitis community, **Fanny Voitzwinkler** representative of TB Coalition and HIV/AIDS representatives **Sini Pasanen**, **Anke van Dam**, **Luís Mendão** and **Ann-Isabelle Von Lingen**, were informed that the European Commission has set out a strategic approach for achieving sustainable development in Europe and around the world (including SDG 3.3.).

PHOTO ESSAY

Hep-CORE study

Having the World Health Organization introducing the first global health sector strategy on viral hepatitis and stakeholders in all regions of the world beginning to gather to bring about the goal of eliminating viral hepatitis as a public health threat by 2030, 2016 was a productive year in the fight against the hepatitis. However, despite the good news, we have stumbled upon the fact that Europe has not been monitored as a whole since its inclusion in the WHO global hepatitis policy report of 2013, later followed up by a 2014 global community response report. In attempt to shed the light on national policies on hepatitis B (HBV) virus and hepatitis C virus (HCV), ELPA has taken action and launched *The 2016 Hep-CORE Report - Monitoring the implementation of hepatitis B and C policy recommendations in Europe*. Hep-CORE is a unique patient-led monitoring tool that engaged patient organizations in providing a full picture of the level of implementation viral hepatitis B and C policy recommendations in Europe and part of the Mediterranean Basin. Hep-CORE study was carried out by a research team led by **prof. Jeffrey V. Lazarus**, from the Barcelona Institute of Global Health (ISGlobal), Hospital Clínic, University of Barcelona, Spain and CHIP, Rigshospitalet, a World Health Organization Collaborating Centre on HIV and Viral Hepatitis, University of Copenhagen, Denmark, on ELPA's behalf. We would especially like to thank all patient organizations that participated in the study, all other stakeholders who provided necessary information and our sponsors, AbbVie Inc, Gilead Sciences Inc, and MSD, who supported the study by unrestricted grants.



Illustration

Hep-CORE is a unique patient-led monitoring tool that engaged patient organizations in providing a full picture of the level of implementation viral hepatitis B and C policy recommendations in Europe and part of the Mediterranean Basin

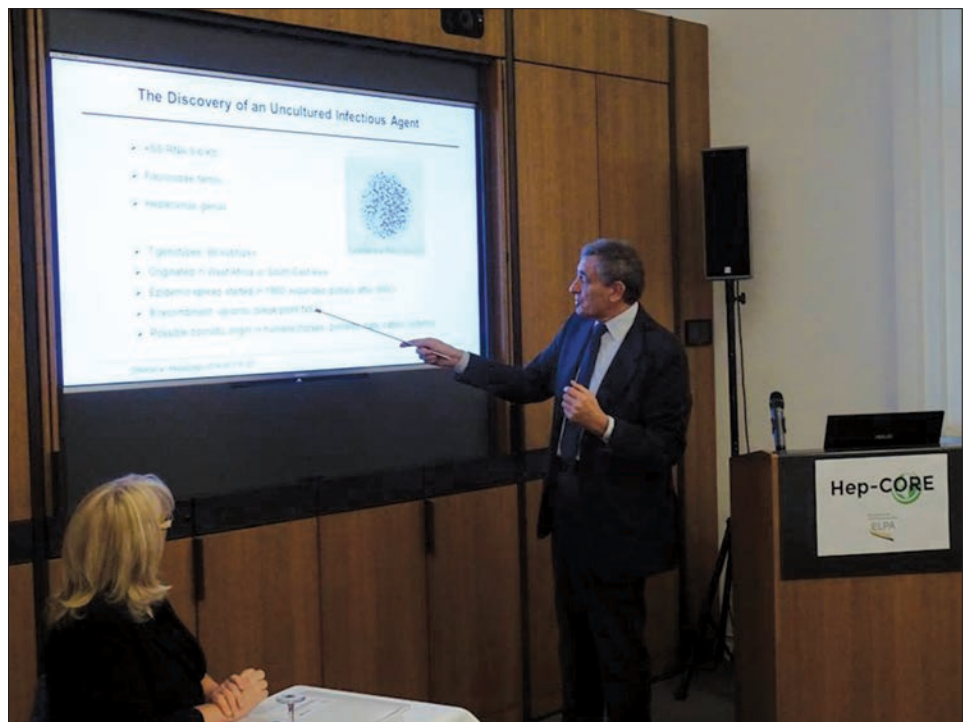
International Hep-CORE Report Launch

Stark findings of the Hep-CORE study were internationally launched on December 20th in Berlin. Results presented by **Prof. Jeffrey V. Lazarus** of ISGlobal, University of Barcelona, showed some worrisome gaps in EU countries policies in coping with viral hepatitis. It shows that 52% of surveyed European (25) and Mediterranean Basin (2) countries lack national strategies to address viral hepatitis B or C, despite the WHO World Health Assembly resolution from May 2016, calling on all countries to have one. Also, only three countries have access to the new, highly effective medicines (direct acting antivirals) for hepatitis C without restrictions. These are just two sobering results from the 2016 Hep-CORE Report on the state of viral hepatitis policy and practice in Europe, released by ELPA. The report also showed that, despite an urgent need for broad monitoring and disease surveillance, 17 countries (63%) have no national hepatitis B virus (HBV) register and that 15 countries (56%) have no national hepatitis C virus (HCV) register. In addition, patient groups from 10 countries (37%) reported that there are no HCV testing or screening sites outside of hospitals for the general population in their countries. Even more alarming, patient groups from 12 of the countries (44%) reported that there are no such sites outside of hospitals that provide testing or screening services for high-risk populations. *“It is completely unacceptable that hepatitis continues to be so poorly addressed in Europe. There are excellent prevention and treatment possibilities, well-thought-out strategies are available, and we have numerous international initiatives, especially from WHO,”* said Tatjana Reic, President of ELPA during the report launch. *“I expect this study to change the landscape of viral hepatitis policy surveillance on a regional, and even global, level.”* – she added. On this occasion, **Prof. Massimo Colombo**, Chairman of the EASL International Liver Foundation and guest at Hep-CORE report launch, emphasized the importance of rigorous HCV surveillance, effective screening programs, increased treatment uptake with high efficacy therapies, and close collaboration between stakeholders. The press conference was opened by a keynote speech of ELPA President, Tatjana Reic and was moderated by ELPA member and Special Policy Consultant, **Achim Kautz**.

Our goal is to repeat Hep-CORE study on a regular basis in order to compare results between countries, and thus help the efforts in elimination of HBV and HCV.



Hep-CORE launch at international press conference, Berlin



Prof. Massimo Colombo at Hep-CORE launch, Berlin



From the left: Prof. Massimo Colombo, prof, Jeffrey V. Lazarus, Tatjana Reic and Achim Kautz at Hep-CORE launch, Berlin



President of ELPA, Tatjana Reic at Hep-CORE launch, Berlin



President of ELPA, Tatjana Reic at Hep-CORE launch, Berlin



Prof. Jeffrey V. Lazarus at Hep-CORE launch, Berlin

PHOTO ESSAY ELPA University

Back in 2015, ELPA created **ELPA University**, a year-long capacity building programme on liver health and advocacy which combines both theoretical learning and skills based trainings. The course, designed in 3 – 4 modules, has been developed to enable ELPA members to confidently advocate for improved liver health services and care within their countries. During the 2016 we have continued with the good practice and organized new school year for 28 patient groups' representatives from 16 organisations, covering 13 countries.



ELPA University students in Belgrade



From the left: Hanna Eloranta, Michael Mogensen and Tove Frisch at ELPA University, Lisbon



Aleksey Lakhov at ELPA University, Lisbon



Robert Mitchell-Thain at ELPA University, Lisbon

Belgrade - Combined modules 4 and 1 for 1st and 2nd Year ELPA University students

First ELPA University 2016 courses were held in Belgrade in May, combining modules 4 and 1 for years 1 and 2. First day in Belgrade all students participated in the joint session ran by Achim Kautz, whilst year 2 participants continued with a three day programme where they learned about liver health in different countries, recruiting community group volunteers, community group fundraising etc. Workshops and trainings were held by **Robert Mitchell-Thain** (PBC Foundation), **George Kalamitsis** (PROMETHEUS), and **Tara Farrell** (World Hepatitis Alliance), well known experts in a liver health community.

Lisbon - IMPACT programme: module 2 for 2nd Year ELPA University students

Having acquired knowledge from the modules held in Belgrade, ELPA University students continued with their programme in Lisbon on September 5th-7th. On this occasion students had the opportunity to listen and learn about developing effective patients' materials and working with media in order to enhance the advocacy for better treatment and care for people living with liver conditions. They were also taught about clinical trials, reimbursement process and policies in EU, as well as how to tackle the stigma which, unfortunately, liver patients often face.



Nikita Kovalenko at ELPA University, Lisbon

Warsaw - IMPACT programme: module 3 for 2nd Year ELPA University students

The beginning of December was marked by the ELPA University IMPACT Programme sequel – module 3. Second year students gathered in Warsaw from 5th to 7th December and continued adopting valuable inputs given by ELPA trainers. This IMPACT Programme, as well as the previous ones, was chaired and managed by **Achim Kautz**.



ELPA University students in Warsaw

2016 HEPATITIS BREAKTHROUGHS



Finally we got it! - Hepatitis community representatives and WHO celebrating Global Health Sector Strategy on Viral Hepatitis at World Health Assembly

WHO's aim to eliminate viral hepatitis by 2030

President **Tatjana Reic** represented ELPA at the 69th World Health Assembly, where 194 Member States governments unanimously voted to adopt the first ever **Global Health Sector Strategy on Viral Hepatitis 2016–2021**. This Strategy sets an important goal of eliminating hepatitis B and C, setting the first milestone for 2021. It includes a set of prevention and treatment targets which, if reached, will reduce annual deaths by 65% and increase treatment to 80%, saving 7.1 million lives globally by 2030. *This is definitely an exciting moment for hepatitis community across the globe and a strong commitment for ELPA to continue its, so far very successful work, but we must have in mind that still a lot needs to be done at Country level, said ELPA President. Carrying a symbolic subtitle Towards ending viral hepatitis, this strategy represents an important set of tools for the elimination of viral hepatitis, an international public health challenge.*

Strategy includes a set of prevention and treatment targets which could reduce annual deaths by 65% and increase treatment to 80%, saving 7.1 million lives globally by 2030.



Adoption of European Action Plan

The WHO Regional Office for Europe, as one of WHO's six regional offices around the world, organized 66th session of the WHO Regional Committee for Europe in Copenhagen on 12–15 September 2016. As a sequel of conclusions adopted in Geneva's Global Health Sector Strategy on Viral Hepatitis 2016–2021, Health ministers and high-level representatives of the 53 Member States of the WHO European Region, partner organizations and civil society endorsed the first *Action plan for the health sector response to viral hepatitis in the WHO European Region*. Plan includes all five hepatitis viruses (HAV, HBV, HCV, HDV, HEV), addressing primarily HBV and HCV. According to the WHO, it is estimated that 171 000 people die each year from viral hepatitis-related causes in WHO European Region. Action plan aims to eliminate this disease as a public health threat in the European Region by 2030 and is aligned with Global Health Sector Strategy on Viral Hepatitis 2016–2021, adopted earlier in 2016.



From the left: Antons Mozalevskis, Tatjana Reic, Charles Gore and Martin C. Donoghoe in Copenhagen



Tatjana Reic and Charles Gore in Copenhagen



Goal of Action plan is the elimination of viral hepatitis as a public health threat in the European Region by 2030.

ADVOCACY AND ENGAGEMENT WITH STAKEHOLDERS

In chronological order

HA-REACT joint action kick-off meeting

The Joint Action on “HIV and Co-infection Prevention and Harm Reduction” (HA-REACT) was launched in Vilnius in January 2016, bringing together 23 Associated Partners and several collaborating Partners to address gaps in the prevention of HIV and other co-infections. ELPA Board member **Milan Mishkovikj** presented ELPA on this kick-off meeting.

APASL 2016: Viral Hepatitis Policy Symposium (Tokyo – 16th February)

Tatjana Reic, on behalf of ELPA, was invited to speak on annual APASL Symposium about *What the inclusion of hepatitis within the SDGs means to Europe*. Her presentation focused on the broad and deep work ELPA has executed with other organizations in order to reach the WHO 2014 Resolution on Hepatitis and HCV Summit and Manifesto in Brussels.

HCV EU Policy Summit

ELPA took an active role during the high level meeting at the HCV EU Policy Summit in Brussels on February 17th. A keynote speech was delivered by **Vytenis Andriukaitis**, Commissioner for Health and Food Safety at the EU Commission, while the introductory remarks were held by **Tatjana Reic**, reminding on Hepatitis C related healthcare costs such as for liver cirrhosis or liver cancer patients, which are in need of a liver transplantation and social costs. She has put forward on what still needs to be done: make innovative treatments affordable, make concrete plans to reach out specific risk groups and increase diagnosis rate efficiently and effectively, find new strategies to prevent and avoid infection and reinfection. President of ELPA asked for a commitment which is still lacking and she proposed a Dublin Declaration to be extended for Hepatitis C. During the first session, another ELPA member, our Special Policy Consultant, **Achim Kautz**, presented the key elements of a successful elimination strategy from a patient's perspective. This first EU HCV Policy Summit was organised by the Hepatitis B and C Public Policy Association in partnership with European Association for the Study of the Liver (EASL), the European Liver Patient Association (ELPA) and the Correlation Network. The Hepatitis C Elimination Manifesto was presented during the Summit.

Hepatitis C: The Beginning of the End

Are we ready to think about the elimination of HCV in Croatia?

High-level meeting was held in Zagreb, gathering more than 100 participants coming from Croatia and the Balkan Region for the first time. The meeting was organized by Croatian Association of Treated and Ill with Hepatitis “**Hepatos**” and **WHO country office**, and was hosted by the EU Parliament member **Biljana Borzan**. The meeting aimed to understand the health care situation related to viral hepatitis, estimating the economic burden of the disease for the future, emphasizing the importance of a National Strategy and the adoption of an Action Plan to fight Viral Hepatitis.

HCV 2020 Forum 2016: Accelerating action

Important stakeholders, including policy makers, health care professionals and patient advocates, gathered on the HCV2020 forum in Barcelona to bring to mind the progress being made in addressing hepatitis C. Through the promotion and sharing of best practices and focus on prevention, early detection, and clinical management of patients, participants contributed towards advancing the control and cure of hepatitis C. Tatjana Reic, representing ELPA, was chairing the plenary session IV: *Good practices at micro level across the whole HCV pathway: preventing and early detection*. The result of HCV 2020 was *HCV HUB Planning and Implementation* launched by the University of Deusto, as a tool to support knowledge transfer and mutual learning among various countries and stakeholders as well as a support for recommendations.

ELPA on VHPB’s Highlight underserved for screening, prevention and treatment of viral hepatitis B and C in Europe

The Viral Hepatitis Prevention Board (VHPB), comprising of number of advisors and honorary top stakeholders in the world of Hepatitis, met in Ljubljana in March to discuss on the following objectives: identify the undertreated groups for screening, prevention and treatment; identify best practices from other countries related to existing models to reach undertreated groups, improve screening, prevention and treatment; discuss strategies to improve access for hard to reach and undertreated groups towards screening/diagnosis/treatment programs and immunization programs. ELPA, as a member of VHPB, was represented by Tatjana Reic who opened the meeting together with **Mojca Maticic**.

Enhancing Value in European Health Systems: Improving Outcome

ELPA took an active role in cross-party initiative which launched a new multi-stakeholder vision document on *Enhancing Value in European Health Systems: the role of outcomes measurement*. The document focuses on the relationship between the ageing populations and the legacy of economic crisis which are confronting health systems across Europe with unprecedented challenges and a strong focus on health outcomes, to improve quality of care for patients and strengthen public health interventions.

WHO Europe Advisory Committee for the EU Action Plan for the prevention and control of HIV/AIDS and Viral Hepatitis

President **Tatjana Reic** and Special Policy Consultant **Achim Kautz** took part in the meeting of the Advisory Committee for the development of European action plan for the prevention and control of viral hepatitis in the WHO European Region, 2016–2021.

Exploratory meeting on a joint stakeholder initiative on HCV

ELPA President **Tatjana Reic** attended an exploratory discussion in London about creating an EU high level stakeholder platform which would serve to work towards effective and appropriate prevention and management of Chronic Viral Hepatitis, in particular the elimination of Hepatitis C. The meeting was also attended by prominent representatives from **VHPB, EASL, HepB&CPPA, EATG and WHA, as well as by prof. Jeffrey V. Lazarus and prof. David Goldberg**. During the meeting it was suggested that in future this platform should be co-chaired by Tatjana Reic and prof. **Pierre van Damme**.

World Hepatitis Day 2016

On July 28th, people throughout the world have celebrated the World Hepatitis day, bringing attention to the further work to be done on the elimination. ELPA representatives marked that day on a press conference in Moscow presenting preliminary results of the Hep-CORE - study launched to assess national responses to viral hepatitis in the region. The data, obtained by surveying ELPA member groups, suggested that some European countries are falling behind in terms of the policies and practices that public health experts and the World Health Organization recommend as the basis for an effective response to the hepatitis B virus (HBV) and hepatitis C virus (HCV) epidemics. Besides presenting the preliminary results, ELPA President **Tatjana Reic** and Board member **Robert Mitchell-Thain** participated in this event in order to support efforts of the patients in Russia who are subjected to even



ELPA representatives with colleagues from Russia

greater discrimination. World Hepatitis day is an important tool in raising awareness of this silent disease and fighting for appropriate treatment standards for all the patients.

HCV Patients' Protest in Bulgaria

Delayed access to the new interferon-free treatment led to the protest organized by patients infected with HCV on August 9th in Sofia, Bulgaria. Protesters claimed their rights in front of the central building of the National Health Insurance Fund (NHIF) who started reimbursing for the new HCV therapies on March 1. According to the law, this institution has a two-month period to consider a submitted patient's treatment protocol prepared by a gastroenterologist but the problem stemmed from the fact that many patients had to wait for the decision of NHIF for 3-4 months and more. Just two hours after expressing their disapproval, patients had their protocols approved by NHIF.

Women in High Places: Leading the Global Challenge of Hepatitis and Liver Cancer Control

Caring ambassadors organized the Women in high places meeting in New York to address the link between hepatitis and liver cancer and invited ELPA to take part in it. Our President Tatjana Reic was recognised and attended this event as well as other representatives from many influential organizations in the field of Hepatitis and Liver Cancer. The meeting took place from September 6th to September 8th

in New York City and has, once again, confirmed that women leaders can be of great value in supporting the fight against hepatitis. This meeting was one example of how women can come together and develop unique and thriving set of tools and visions to enrich and enhance our collective efforts in hepatitis elimination.

Project PBC Educational day

As a part of the PBC International day, which was marked on September 11th, ELPA made its contribution holding the PBC Educational day on September 4th. Project leader **Robert Mitchell-Thain** gave a lecture about PBC, PSC and AIH aiming to educate gathered participants on rare liver diseases. PBC Educational day was created and implemented by ELPA team who work hard in drawing attention to the liver diseases and was granted by winning the Practice to Policy Program by Intercept. PBC International day is marked with a goal to raise the awareness and to increase public understanding on PBC.

Presenting the patients' perspective at EASL Special Conference

Our Public Affairs Director **Livia Alimena** presented *The roadmap for cure – The patients' perspective* at AASLD – EASL special conference in Paris between the 23rd - 25th of September. ELPA was also represented by our member Andrei Baiceanu who later on, as the participant, has devised and sent out an interesting report with conference's highlights and insights. The European Association for the Study of the Liver (EASL) hosted a Special Conference regarding Hepatitis C Virus (HCV) infection called Roadmap to Cure and brought together many hepatologists, virologists, researchers and health professionals to discuss the EASL Treatment Recommendations Guidelines and outline the goals in order to increase patients' access to treatment. EASL Treatment Guidelines for HCV presented some great achievements in hepatitis research reached in the last two decades. For example, it is the first time in EASL's history that the HCV Guidelines do not have Interferon-based treatments. Also, another crucial point was discussed during the meeting - the need to increase screening for HCV to be able to diagnose and treat more patients as well as to decrease the rates of HCV infection worldwide.

WHO Regional Technical Consultation in Minsk

Regional Technical Consultation on dissemination of the WHO guidelines on HIV and Viral Hepatitis for 12 Eastern European and Central Asian countries took place from September 26-29 in Minsk, Belarus. Main goals and expectations of the meeting, among other, were to explain technical elements of the new 2014/15 WHO's consolidated guidelines for HIV and Hepatitis and to provide an opportunity for

well-informed WHO and MOH staff to discuss new policy recommendations. ELPA was represented by President Tatjana Reic who co-chaired a session on WHO guidelines on Viral Hepatitis, surveillance and testing. In her introduction speech she addressed the participants to show to Eastern European and Central Asian countries that the efforts made by patients organizations ELPA countries so far, are visible and yielding tangible results.

Second exploratory Stakeholders' meeting on viral hepatitis elimination

On October 17th ELPA's President **Tatjana Reic** chaired a stakeholders' meeting on a consensus initiative to promote hepatitis elimination in Europe. Delegates like **Pierre van Damme**, VHPB; **Antons Mozalevskis**, WHO; **Luis Mendao**, EATG; **Jeffrey V. Lazarus**, University of Copenhagen; **Massimo Colombo**, EASL Foundation; **Katrin Schiffer**, Correlation Network Hepatitis C; and **Raquel Peck**, WHA prompted the discussion which resulted in forming a unique viewpoint: will to support the elimination of viral hepatitis in the WHO Region with a focus on hepatitis B and hepatitis C in view of the high impact on morbidity and mortality, to generate political will amongst EU and national decision-makers to eliminate viral hepatitis as a public health threat, focus on surveillance, prevention, testing, access to affordable treatment and many more.

Call to Action to improve Organ Donation and Transplantation across the EU

ELPA has participated in a multi-stakeholder cross-condition meeting, held in the European Parliament to discuss how to improve organ donation and transplantation across the EU. Hosts of the meeting were MEPs **Ivan Jakovcic**, **Alojz Peterle**, **Romana Tomc** and **Hilde Vautmans**. The purpose of the meeting was to exchange ideas and experiences between institution representatives and transplanted patients. ELPA's representatives were **Tatjana Reic**, **Angelika Widhalm**, who has contributed to the meeting with her experience and vision of the organ donation and transplant situation in EU and **Lana Crnjac**.

Georgian HCV Elimination program, second TAG meeting

ELPA's President Tatjana Reic chaired the session *"Promote Advocacy, Awareness & Education, Focus on Stigma and Discrimination"* during the HCV Elimination plan second Technical Advisory Group meeting in Tbilisi, Georgia on October 25th and 26th. The two day meeting began with presentations from Georgian MOH representatives, who provided TAG members with information about a problem of viral hepatitis in that country and was followed by discussion of elimination plan aspects.

ELPA at Country Meeting in Albania

On October 27 and 28 Tirana hosted eminent European professionals working on elimination of viral hepatitis on the conference: *Prevention & control of Viral Hepatitis in Albania and the neighbouring countries: lessons learnt and the way forward*. Main objectives of the sessions were to provide an overview of surveillance systems for viral hepatitis and infectious diseases as well as to discuss the further development and the implementation of a National hepatitis plan. ELPA President **Tatjana Reic** was one of the chairpersons while several ELPA members contributed to the meeting agenda as well: **Zdenko Simonovic** B18 (Bosnia and Herzegovina), **Milan Mishkovikj** Hepar Centar Bitola (Macedonia) and **Ivana Dragojevic** from Hronos (Serbia).

HA-REACT 2nd Advisory Board meeting

After having participated in January's kick-off meeting and the launch of the initiative, **Milan Mishkovikj**, on behalf of ELPA, participated in HA-REACT's Advisory Board meeting held in Riga. As a reminder, The Joint Action on HIV and Co-infection Prevention and Harm Reduction (HA-REACT) addresses existing gaps in the prevention of HIV and other co-infections, especially tuberculosis (TB) and viral hepatitis, among people who inject drugs (PWID).

Nordic Program - Launch Meeting

10th of November was reserved for Nordic Groups Meeting where ELPA's President Tatjana Reic and Public Affairs director **Livia Alimena** were invited as speakers. Tatjana Reic held a presentation Time to Deliver Programme - The Road to Improved HE care, while Livia Alimena addressed the participants with her presentation on HE Advocacy Tool kit. RHC, ELPA member from Sweden, was represented by **Tove Frisch** and **Michael Mogensen** who gave their insights into HE Care in their country as well as participants, i.e. patients' representatives, from Denmark.

ELPA at The Liver Meeting 2016

This year's Liver Meeting organized by AASLD was held in Boston, USA from November 11-15. Among more than 9,500 hepatologists, health professionals, community and patients' representatives and other stakeholders from across the world, ELPA as well had its representatives: **Tatjana Reic**, **Livia Alimena** and **Marko Korenjak**, who had the opportunity to hold the meetings with key stakeholders. While the main purpose of the meetings was fundraising they were able to also exchange thoughts on the latest liver diseases research, discuss treatment outcomes, and interact with colleagues. **Robert Mitchell-Thain**, ELPA Board Member, participated representing his organization, as well as some other ELPA members like Ingo **Van Thiel** and **Marco Bartoli**.

Supporting Awarh campaign 2016 and Health Attaché breakfast meeting

Awareness Week on Alcohol-Related Harm (AWARH) was organized from 21 – 25 November 2016. The focus of this year's AWARH was on the ongoing revision of the Audio-visual Media Services Directive (AVMSD) which provides an opportunity to free Europe from health-harmful marketing. During the AWARH several activities were organized, such as health Attaché breakfast meeting which was attended by ELPA's President Tatjana Reic. There was also organized a thunderclap campaign with a social reach of 156.419,00 people

WHA Regional Board Member elections

We are proud to say that two ELPA members were nominated and elected in the WHA Regional Board Member Elections: EURO Regional Board Member: **Ivana Dragojević**, President of HRONOS and Eastern Mediterranean Regional Board Member: **Ammal Metwally**, Association of Liver Patient Care (ALPC-Egypt).



Ivana Dragojevic



Prof. Dr. Ammal Mokhtar Metwally

Finland adopting Hepatitis C strategy for 2017-2019

Finland has taken an important step as The Ministry of Social Affairs and Health has published the hepatitis C strategy for 2017-2019. Nearly 30,000 hepatitis C cases have been recorded in Finland as approximately 1,150 new cases are reported to the National Infectious Diseases Register annually yet hepatitis is still a silent disease in Finland as those infected are confronted daily with unreasonable prejudice, which is why many do not want to reveal their condition. The hepatitis C strategy aims to improve hepatitis C prevention and to establish guidelines for testing and treatment practices in order to harmonize long-term care for all who have hepatitis C. The initial objective during 2018 is to expand the treatment in replacement therapy to include those with hepatitis C who fulfil the treatment criteria. The long-term

goal is treatment for all carriers of hepatitis C, regardless of the degree of liver damage, in order to limit new infections. Finnish Kidney and Liver Association pointed out that, at the moment, awareness raising and preventive work has not been given the sufficient resources however they hope this new strategy will change things as more than half of all new infections occur among people under 30 years of age. The strategy published by the Ministry of Social Affairs and Health can be found in Finnish at: <http://julkaisut.valtioneuvosto.fi/handle/10024/78923>

Advisory Board Meeting in Warsaw

This year's ELPA Advisory Board Meeting was held in Warsaw on the 7th and 8th of December, just after the completion of ELPA University Module 3. On this occasion, representatives from Gilead Sciences, Bristol-Myers Squibb, Intercept, AbbVie and Merck & Co., Inc presented their latest scientific developments and replied to ELPA member's questions. While meeting was moderated by Program Manager **Marko Korenjak**, all introductions to the industry presentations were made by **Ingo Van Thiel**, ELPA's Scientific Team Member.

ELPA's participation at EATG's Policy Meeting on Access to DAAs in EECA

On 10th and 11th of December Public Affairs Director, **Livia Alimena**, participated in Policy Meeting on Access to DAAs in EECA in Tbilisi, Georgia, organized by European Aids Treatment Group (EATG). While the first day was reserved for meetings with industry (Janssen, MSD and Gilead) second day of the meeting was marked by WHO Global Hepatitis Strategy and WHO regional Action Plan for the European region, presented by WHO's **Antons Mozalevskis**.

ELPA at PBC PAN EURO Advisory Board

PBC Advisory group kick-off meeting was held on December 13th. The main purpose of the meeting was to give advice on how Intercept can support the PBC community to meet their current advocacy and education priorities and on the need and rationale for a pan-EU PBC network. ELPA's President **Tatjana Reic** represented ELPA on this occasion whilst some ELPA members like organizations from Italy, Finland and Germany participated as well. Our Board member **Robert Mitchell-Thain** presented the work and notable results of his PBC Foundation during this meeting which was moderated by **Achim Kautz**, our special Policy consultant.

ELPA Stakeholders' meeting

This year's Stakeholders meeting (previously known as Policy meeting) took place in Berlin on 19th of December and has gathered more than 30 professionals – patients, industry representatives and other stakeholders. Meeting was opened with ELPA President **Tatjana Reic's** review on 2016 and its accomplishments, and was moderated by **Marko Korenjak**, ELPA Program Manager and **Achim Kautz**, ELPA Special Policy Consultant. Throughout the day and during the presentations held by ELPA team, participants were able to hear about what has been done so far in ELPA from its beginnings. ELPA team was proud to show results which prove that ELPA's plans and strategies are achieving its goals since the day one. In order to assure further progress, Marko Korenjak informed attendees on planned activities in 2017, explaining them in detail while introducing ELPA Work plan for 2017. Other ELPA members like **Prof. Dr. Ammal Mokhtar Metwally** (Egypt), **Julio Burman** (Israel), **Livia Alimena** (ELPA) presented key activities as well.



Advisory Board Meeting participants in Berlin

WORKSHOPS AND TRAININGS

WHO workshop: *Better Food for Better Health*

European Parliament on February 16th.

ELPA attended the workshop organized by the WHO Regional Office for Europe, co-hosted by **Mairead McGuinness**, Vice President of the European Parliament, MEP and by **Biljana Borzan** MEP, in collaboration with the Netherlands EU Presidency.

ELPA Strategy Workshop

Frankfurt – 6th April

Several ELPA members met in Frankfurt to discuss and devise new ELPA strategy 2017-2020.

EMA trainings in London

Board member **Marko Korenjak** and ELPA member **Andrei Baiceanu** attended EMA trainings which took place in London on 29th and 30th of November. During the “Annual training day” they had the opportunity to introduce new patient/consumer representatives to the EMA and to gain experience in the procedures they might encounter in their work. Second day was dedicated to the PCWP meeting.

LOOK INTO THE FUTURE

ELPA Strategy 2017-2020

European Liver Patients' Association Strategy for 2017-2020 was carried out by ELPA executive team during 2016. Our continuous striving towards improvement keeps us involved in devising even newer and more innovative approaches that will underpin our efforts and meliorate our results. New ELPA three-year strategy focuses on strengthening our mission, values and our established procedures which stand as the pillar of our organization. In addition, recognising the importance of increasing the capabilities of our members, forthcoming period will be dedicated primarily to the member empowerment which will later on help us in strengthening our position in the policy work that needs to be done. We are looking forward to this journey and its outcomes aimed to aid patients and their families.

ELPA GOVERNING BOARD AND SECRETARIAT

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. The Board and the Secretariat work together towards making ELPA's vision a reality.

In 2016 ELPA's work was carried out by:

Governing Board:

Tatjana Reic, President

Marinela Debu, Vice President

Angelika Widhalm, Vice President

Robert Mitchell-Thain, Member of the Governing Board

Milan Mishkovicj, Member of the Governing Board

Marko Korenjak, Member of the Governing Board (co-opted)

Nadine Piorkowsky, Former President and Honorary Governing Board Member

Scientific Committee:

Ivan Gardini

Hilje Logtenberg-van der Grient

Ingo van Thiel

Andrei Baiceanu

ELPA Policy Work

Achim Kautz, Special Policy Consultant

Executive team and Secretariat:

Program Manager, Marko Korenjak

Livia Alimena, Public Affairs Director

Lana Crnjac, Office and Communications Manager

Nathalie Krone-Seywald, Event Manager

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 (ELPA Balance Sheet, Accounts and Funding Sources 2016) 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 2016 ELPA received restricted and unrestricted grants as well as, in some cases, in-kind support, from the following companies:

abbvie

 GILEAD

 MSD

janssen 



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