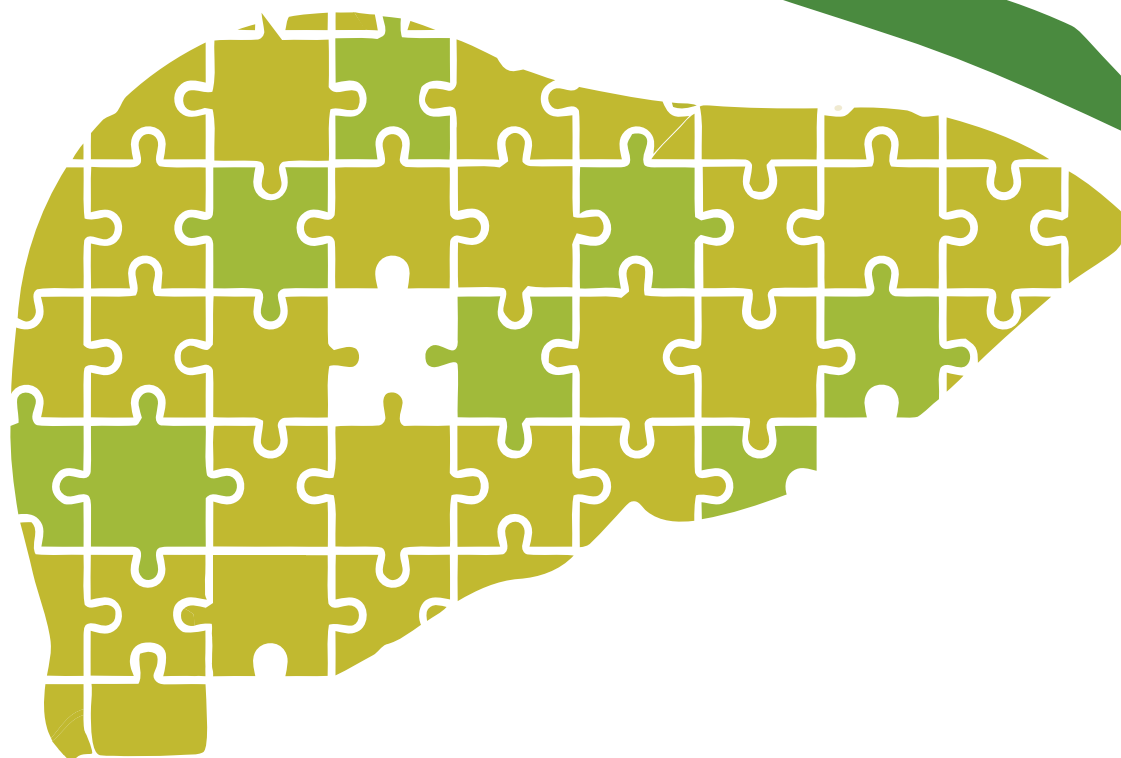
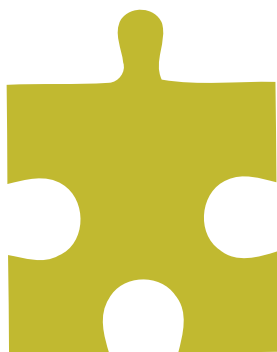


European Liver  
Patients Association

# ELPA



**11 Years**  
of Advocating  
for Liver Health



ANNUAL RAPORT  
**2015**

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## **STAKEHOLDER MEETING**

**11 Years**  
of Advocating  
for Liver Health





# Liver means Life

## INTRODUCTION

Dear friends and colleagues,

Today, ELPA represents the interests of thousands of patients through its fast-growing membership of 35 associations from 27 countries across and beyond Europe.

Over the years, we have dedicated time and human resources to defend the patient's rights to early diagnosis and access to timely treatment with the latest therapeutic treatments. Our leadership and active involvement in projects aimed at improving liver health literacy contributed significantly at public awareness rising on liver disease prevention and management.

Our support to the ELPA Members enhanced their capacity to respond to the challenges posed by a dynamic environment of remarkable scientific progress hindered by limited public funds and competing demands of the different health issues. Our role as a mediator of a diverse and growing network of partners and stakeholders facilitated partnerships and opened doors to new action possibilities.

Within its first decade, ELPA transformed itself considerably – from a hub of likeminded patients who identified common concerns and shared best practices, to a communication platform between patients, partners and other interested stakeholders for the sake of a brighter future for the vulnerable liver patient.

ELPA takes pride in being recognised as a key player in the field of liver disease advocacy!

Yet, the future is far from bright. In times of political and economic instability in Europe, the attention to the neediest patients is again diverted to others. Whilst “elimination” of HCV is still a distant dream.

In fact, the insecurity demands us more responsibility, to speak louder and to grow stronger and more determined to remain in the focus of political decisions.

We shall continue to work in line with our vision: for a world without liver diseases!

Sincerely,

TATJANA REIC  
ELPA President

## ELPA Elects a New Board

The Annual General Meeting took place on 24th of April during the International Liver Congress of EASL in Vienna. The ELPA members had to vote for President and Steering Committee. The ELPA members re-elected Mrs. Tatjana Reic as a President to serve for another four-year term.

### The composition of the ELPA Board is as follows:

President: **Mrs. Tatjana Reic**  
Vice-president: **Mr. Ivan Gardini**  
Treasurer: **Mrs. Angelika Widhalm**

Member: **Mrs. Marinela Debu**  
Member: **Mr. Milan Mishkovikj**  
Member: **Mr. Robert Mitchell – Thain**  
Honorary Member: **Mrs. Nadine Piorkowsky**

## ELPA Members in 2015

<u>AUSTRIA</u>	HAA – Hepatitis Aid Austria
<u>BELGIUM</u>	VHC – Vlaams Hepatitis Contactpunt
<u>BOSNIA &amp; HERZEGOVINA</u>	“B18” - The Chronic Viral Hepatitis Patients Association
<u>BULGARIA</u>	HepActive Hepasist - National Association for Fighting Hepatitis
<u>CROATIA</u>	HEPATOS – Croatian Association For The Liver Diseases
<u>EGYPT</u>	ALPC - Association of Liver Patients' Care
<u>FINLAND</u>	The Finnish Kidney and Liver Association
<u>FRANCE</u>	Fédération SOS hépatites
<u>GERMANY</u>	Deutsche Leberhilfe e.V. Deutschen Hepatitis C Forum e.V.
<u>GREECE</u>	“Prometheus” Hellenic Liver Patient Association
<u>HUNGARY</u>	VIMOR - Hungarian Association of Chronic Hepatitis Patients
<u>ISRAEL</u>	Hetz – Israeli Association For The Health Of the Liver
<u>ITALY</u>	Associazione EPAC Onlus
<u>LITHUANIA</u>	Infectious Diseases Patients Association LIDPA
<u>MACEDONIA</u>	Hepar Centar – Bitola HEPTA - Association for health education, prevention and better treatment
<u>NETHERLANDS</u>	NLV - Dutch Liver Patients Association
<u>POLAND</u>	Star of Hope Foundation
<u>PORTUGAL</u>	SOS Hépatites Portugal
<u>ROMANIA</u>	APAH-RO Sano-Hep
<u>SERBIA</u>	HRONOS Liver patients association
<u>SLOVAKIA</u>	HEP HELP KLUB
<u>SLOVENIA</u>	SLOVENIA HEP - Slovenian Association of patients suffering from hepatitis
<u>SPAIN</u>	ASSCAT - Catalan Association of Hepatitis Patients FNETH - National Federation of Liver Patients and Transplanted
<u>SWEDEN</u>	RHC - Riksföreningen Hepatit C
<u>TURKEY</u>	HEPYAŞAM – Living with Hepatitis Association
<u>UK</u>	British Liver Trust Hepatitis C Trust Liver4Life PBC Foundation
<u>UKRAINE</u>	Stop Hepatitis

At ILC, the ELPA members also voted in favour of the accession of a new member association: Slovenian Association of patients suffering from hepatitis SLOVENIA HEP. With the newly associated member, the ELPA family grows to 35 members from 27 countries.



## SYMPOSIUM 2015



The symposium took place during the International Liver Congress in Vienna on 25th of April 2015.

The first part of the symposium continues this burning debate from 2014, from a public health view as well as from the perspective of patients and doctors.

The second part of the symposium looked into the crystal ball, and asked a question that is already on many minds: "What comes next after hepatitis C?".

The opening session was made by Tatjana Reic, and the presentations were: "Addressing the global burden of viral hepatitis infection" by Stefan Wiktor MD from WHO and "Hepatitis B in the Past and the Future - Out of the Shadow of HCV?" by Karsten Wurstthorn and Jorg Petersen.

## The "C: My Journey" Tool

ELPA launched a new tool, designed specifically for patients with hepatitis C. It was developed to address the individual needs of patients, "C: My journey" invites visitors to the ELPA website to answer questions about their condition so that the information they receive is tailored to their specific requirements.

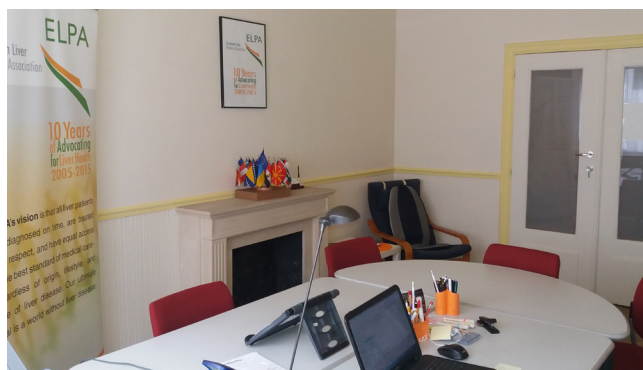
The tool was officially launched at the International Liver Congress of EASL in Vienna in April 2015. Its purpose is to collate the extensive and disparate information available online in one central place so that access to the right information at the right time can help patients to better understand and manage their condition.

Patients can access the tool from the ELPA website in four additional languages: Macedonian, Turkish, Romanian and Bulgarian. A Hungarian language version

of the tool is to be launched shortly in 2015. These languages were chosen, based on the level of resources currently available to the patients in these countries. However, it is hoped that the tool will be translated and rolled out further in the future.

The burden of hepatitis C across Europe is huge with over nine million people currently infected and tens of thousands of new cases being diagnosed each year. Recent developments in the hepatitis C treatment promise a realistic chance for a cure. Now more than ever, patients need access to current and accurate information to guide them through discussions with their physician and their treatment journey.

## Opening of the new ELPA office in Brussels



The 10th anniversary of ELPA was marked by another significant event in the history of the association – the opening of ELPA's office in the heart of Brussels. Officially launched in May, ELPA welcomed patients and partners to a cocktail event at its new address – 235 Rue de la Loi.

The event symbolized the beginning of a new era for ELPA. With its fast growing number of members and the demand for proactive engagement in the wider scope of liver diseases, ELPA moves decisively into the day-to-day advocacy work with the EU institutions and Brussels-based stakeholders to promote and defend the rights of all patients with liver diseases.

## ELPA launched two key reports in Brussels

On 20th May, ELPA launched two key reports which further highlighted the importance of tackling the hepatitis burden with decisive measures, both at the national and the EU levels. The reports are "Hepatitis B and C: An Action Plan for Saving Lives in Europe" and the "Burden of hepatitis C in Europe" based on France and Romania. These reports are milestones in ELPA's work and serve as the cornerstone for the work of patient advocates. The launch event gathered experts from WHO, EASL, VHPB, the Correlation C network, and patient representatives from the 27 ELPA member countries, together with other stakeholders working in the field of liver disease.

In her welcoming remarks, Mrs. Tatjana Reic, President of ELPA, expressed her pride at the commitment of the key stakeholders in the field to inspire action on viral hepatitis by providing not only a concise document of recommendations for action, but also the economic burden model, which highlights the value of increasing treatment rates for a limited length of time.

## ELPA University



In 2015, ELPA launched ELPA University, a year-long capacity building programme on liver health and advocacy which combines both theoretical learning and skills based training. The yearlong course, designed in 3 – 4 modules, has been developed to enable 20 ELPA members in 10 countries to confidently advocate for improved liver health services and care within their countries.

Equipped with practical knowledge and improved skills from Module I – "A practical introduction to liver health and liver health advocacy across Europe" (17-21 May, Brussels), the participants headed to Split to take part in Module II – "Advocating for better treatment and care for people living with liver conditions" (23-26 August).

Module III ("Approaches to targeted fundraising and NGO management"), which took place in Zagreb, provided an opportunity for gaining practical advice on fundraising and interaction with stakeholders. Module IV ("How to implement ELPA University learnings") will be held in early 2016 together with Module I of Year 2.

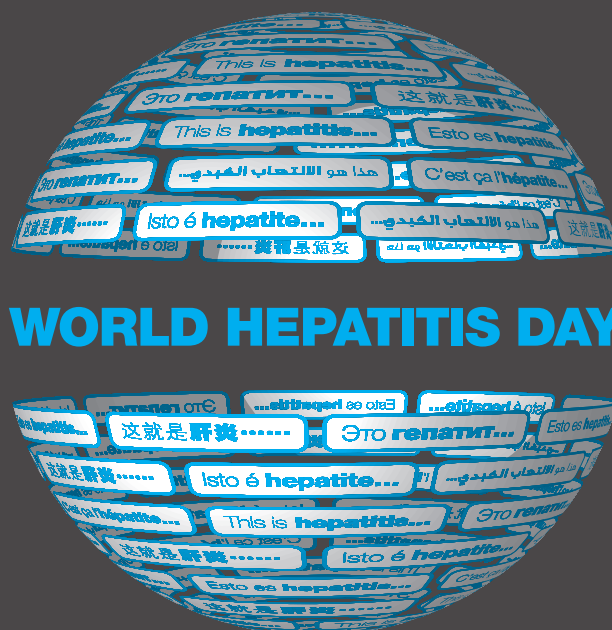




## ELPA Members celebrate WORLD HEPATITIS DAY 2015

WHD 2015 was a great opportunity for rising awareness in countries where ELPA is represented by its members. Numerous activities like press conferences, disseminating materials, joint actions, celebrity engagement and public lunch to screening activities of wider public took place as well as a screening during Ultra Europe festival in Split where tens of thousands of young people came from across the globe to enjoy the summer festival.

Because of abovementioned numerous activities, only our newest member is privileged to be listed in this year's annual report.



## SLOVENIA

### Slovenian Association of Patients Suffering from Hepatitis SLOVENIA HEP

On July 8th, Slovenia Hep gathered journalists, medical specialists, industry representatives and the general public at a press conference to announce the decisive action of the government to provide access to the latest generation of interferon-free regimen for the treatment of Slovenian patients with HCV. The new treatment will be available from September 2015.

The event, held at the Department for Infectious Diseases of the Ljubljana University Hospital, marked the successful and fruitful collaboration between doctors, patients and the public authorities. Mrs. Tatjana Reic, President of ELPA, who presented data on the achievements and challenges in other EU countries, expressed her delight with the affirmative action of Slovenia in recognition of the rights of patients with HCV. Prof. Dr. Matičič Mojca, a leading medical expert in the hepatitis field, also voiced her satisfaction with the remarkably positive developments.

Mr. Marko Korenjak, President of Slovenia Hep, was delighted with the effective cooperation between the stakeholders. With determination and enthusiasm, he committed to continue the dialogue and collaboration with the partners to raise awareness on the

prevention of viral hepatitis among the public and ensure that patients have access to quality information on the new screening and treatment possibilities in Slovenia.

The Slovenian Association SLOVENIA HEP, helping patients suffering from hepatitis, is the youngest ELPA member, acceded at the ELPA Annual General Meeting in April 2015.



## ELPA Screening Activities



Viral hepatitis is, especially in Eastern European countries, not high enough in the political agenda. Bearing in mind that most ELPA members in those countries are not wealthy enough to lead on awareness-raising activities, especially among the so called at risk populations, in 2015 ELPA decided with the support of Gilead, to help ELPA members with their screening activities. Members from Ukraine, Hungary, Slovakia, Poland, Bosnia & Herzegovina, Bulgaria, Croatia, Macedonia, Lithuania, Romania, Serbia, and Slovenia were invited to apply for support.

By the end of 2015, ELPA had distributed more than 2.000 tests to ELPA members in Bulgaria, Croatia, Macedonia, Romania, Serbia, Slovenia and Hungary where various screening activities were conducted successfully. Gilead kindly supported this ELPA activity. 2025 tests have been procured and there have been organized testing for: prison inmates and injecting drug users (252 persons tested, 10 anti HCV positive), general population; especially those who have been hospitalized and have received blood transfusions (515 persons tested, 18 anti HCV positive), general population during World Hepatitis Day (WHD) 2015 (138 persons tested, 10 anti HCV positive). A full report will be presented at the end of project in Q2 2016.



## 3rd Awareness Week on Alcohol-Related Harm (AWARH)

The third "Awareness Week on Alcohol-Related Harm" (AWARH) event was held 16th - 20th November 2015 in Brussels. The Secretariat held for the second year by ELPA, organized two separate events – one event on Alcohol Policy at the European Parliament (17th November) and a closed breakfast meeting of Health Attachés at the Luxembourg Permanent Representation.

Both events highlighted the overwhelming burden of alcohol-related harm in Europe, suggesting possible solutions to the problem and how to be a catalyst for debate at European and national levels.

The Awareness Week on Alcohol Related Harm (AWARH) is an initiative of: the European Alcohol Policy Alliance (EUROCARE), the European Association for the Study of the Liver (EASL), the European Brain Council (EBC), the European Liver Patients Association (ELPA), the European Federation of Associations of Families of People with Mental Illness (EUFAMI), the European Federation of Addiction Societies (EU-FAS) and United European Gastroenterology (UEG). The purpose of the initiative is to highlight the negative effects of alcohol and call for greater policy action to address the problems caused by it, through improvements in prevention, education, screening and treatment and adequate service.

Hosted by MEP Jytte Guteland (S&D), the EP meeting gathered a number of distinguished speakers, including Deputy Director General Martin Seychell from the European Commission Directorate General Health and Food Safety, Health Attaché Tairi Täht (Ministry of Social Affairs, Estonia) as well as representatives from the OECD and the European Brain Council (EBC).

A number of Health Attachés joined the meeting at the Luxembourg Permanent Representation on 20th November. Policy-makers, public health organizations and patient advocates joined the meeting reinforcing the reality that harmful alcohol consumption has negative impact on public health, economic sustainability and social wellbeing. However, despite the overall consensus over the need for greater policy action, there is a lot to be done to address the issue in a systematic and decisive manner to ensure clear actions and distribution of responsibilities both at the EU and the national level.



## Viral Hepatitis and Your Body

Viral Hepatitis and Your Body International Training Day took place in Vienna, Austria, 26th – 27th November 2015. It is a program, which has been developed and funded, by Gilead Sciences Europe Ltd. in a partnership with ELPA, as a service to medicine for community advocates and allied health care professionals in the area of viral hepatitis.

The initiative specifically aims to address the unmet needs of people living with viral hepatitis, assisted by an International Taskforce of 11 specialists and 40 patient group representatives from 20 countries.

The training was focused on three key areas of viral hepatitis:



- viral hepatitis and extra hepatic manifestations (Hilje Logtenberg, LvdG consultancy, Netherlands),
- viral hepatitis and adherence (Achim Kautz, Bundesarbeitsgemeinschaft Leber, Germany, Tove Frisch, The national Union of Hepatitis C, Sweden),
- viral hepatitis and psycho-social impacts (Marko Korenjak, ELPA, Slovenia, Uroš Rajakovic, HROnOS, Serbia).

## Stakeholders' Meeting



This year's ELPA Stakeholder Meeting (formerly known as "ELPA Policy Meeting") took place on 28th November in Vienna. The meeting provided a platform for exchange of ideas and proposals and synchronization of activities of relevant liver disease stakeholders. More than 40 participants attended the meeting, including representatives from WHO, EASL, VHPB, EATG, Correlation network, ELPA members and pharmaceutical industry.

Following an update on the ELPA activities for 2015 and a preview of our Work Plan for 2016, ELPA President Tatjana Reic opened the floor to Mr. Antons Mozalevskis (WHO Regional Office for Europe). He presented the Action Plan for the Prevention and Control of Viral Hepatitis in the WHO European Region 2016–2021 aiming at the reduction of viral hepatitis transmission as well as the related morbidity and mortality rates. Mr. Mozalevskis highlighted the ambitious strategy including five strategic directions (strategic

information for focus and accountability; interventions for impact; delivering for equity; financing for sustainability and innovation for acceleration). This action plan requires the active involvement of local stakeholders who need to promote the strategy and support their governments in the implementation at the national level.

ELPA invited EASL, VHPB, EATG, and the Correlation network to present on selected past and future activities and discuss possibilities for future cooperation. The highlight in the agenda was the new project of ELPA, "Hep-CORE" presented by Prof. Jeffrey Lazarus. Drawing the conclusions of "The Hepatitis B and C: An Action Plan for Saving Lives in Europe", it intends to highlight the gaps between state-of-the-art practices and on-the-ground realities in viral hepatitis management and assess the level of compliance of selected European and Mediterranean countries with the international hepatitis B and C recommendations.



## Time to DeLiver Campaign

In 2015, with the support of Norgine, ELPA launched the campaign called "Time to DeLiver", aimed at raising awareness of hepatic encephalopathy (HE). HE is a debilitating condition that affects up to 40% of patients who suffer from advanced chronic liver disease. The campaign that comprises a report, which provides information on HE and a call to action, was launched in the European Parliament at an event hosted by Anneliese Dodds MEP on 12th October. Further information about the "Time to DeLiver" campaign see at

<http://www.elpa-info.org/elpa-news---reader/items/elpa-launches-call-to-action-report-for-the-treatment-of-hepatic-encephalopathy.htm>

## Policy work

The ELPA representative for policy work is Achim Kautz supported by Lyliana Chavdarova.

Mr. Kautz started his work in January 2015 with an exchange meeting with ECDC in Stockholm, conferring about better monitoring in Europe. He then attended in February the official annual networking meeting as a speaker.

Mr. Kautz had two differentiate pricing meetings in Brussel in February and in June this year, conferring about different pricing for countries within Europe.

In February there was pre-launch of the economic burden Report in Bucharest as well as a launch of the friends of the liver group in the European Parliament.

In March, Mr. Kautz attended following meetings:

- IEEPO meeting Roche
- Meetings with the Serbian Ministry of Health concerning the policy strategy plan
- Finnish Parliament meeting to increase awareness for the strategy plan
- APASL meeting in Istanbul as a speaker in the policy group

In April, Mr. Kautz attended the EASL ILC event in Vienna as speaker in the main policy session while in May he took part at a Finnish round table concerning HCV as moderator.

In June, as mentioned above there was a differentiate pricing meeting in Brussel and a global virus hepatitis meeting in Berlin, Mr. Kautz was involved as speaker in the main policy session.

## ELPA's Scientific Committee

**The three ELPA Scientific Committee members are:**



**Ivan  
Gardini**



**Ingo  
van Thiel**



**Hilje  
Logtenberg-van der Grient**

Ivan Gardini, Ingo van Thiel and Hilje Logtenberg-van der Grient lead the ELPA Scientific Committee. In 2015, the committee had major contributions to the revision and implementation of important documents related to hepatitis C issues. The most important fields of actions were:

- The revision of the clinical protocol for a new hepatitis C antiviral, the revision document for an approved hepatitis C antiviral, revision of Package Leaflets for an approved hepatitis C antiviral, revision EPAR summary for an approved hepatitis C antiviral, Scientific advice on trials with a new drug on HCC.
- Participation as EMA member to a working group that had as topic: "Recommendations from the PCWP topic group on acknowledging and promoting visibility of patients' input in the Agency's activities".
- Participation at SWAP meetings in March 2015 and in November 2015.



## Advocacy and engagement with stakeholders

- At the beginning of the year ELPAs President and Vice president had, together with several other activists from all over the globe, a meeting within Gilead's headquarters in Foster city, California
- ELPA had an active role within WHO as a member of Hepatitis Civil Society Reference Group with the purpose to help WHO to develop a global strategy. During 2015 several TCs were held, as well as a face to face meeting in Geneva on 7th – 8th May 2015



WHO Hepatitis Civil Society Reference Group



"Hep girls" all born on 28 of July

- 23rd – 26th June in Copenhagen the Consultation on the WHO Global Health Sector Strategies on HIV and Viral Hepatitis were held. Following the consultations, a meeting of representatives of civil society for the WHO EURO region was organised, with the aim of establishing European Regional Civil Society Reference Groups for viral hepatitis and (HIV).



- MEP Friends of liver group was re-established in EU Parliament in May 2015. On this occasion Ms Tatiana Reic, ELPA President, gave an overview about the patient's perspective. She explained that liver diseases are diagnosed too late while early diagnoses are exceptional. She criticized the fact that Hepatitis C is on the radar of the EU, but not necessarily in a constructive way and called for more treatment, better drugs and less burden on countries in her closing remarks.





- The Viral Hepatitis Prevention Board was actively engaged in June 2016 in London and in November 2016 in Riga. The participation of the ELPA president as VHPB advisor in Riga, was a great opportunity to help Latvian patients' in their 3,5 years long campaign and lobbying activities resulting in no more co-payment of 25% for hepatitis treatment as well as introduction of new DAAs.
- During the 9th World Congress of Science journalists with the theme "Expanding our Horizons", ELPA contributed with a lecture during the WFSj mini Symposium on the topic of patient's perspective. ELPA provided, due to knowledge and experience, valuable insight for media representatives from all over the world. All global regions face unique challenges regarding HCV and journalists must navigate those HCV-related and region-specific reporting obstacles. The objective of this initiative was to help journalists around the globe to interpret, question and link HCV-related information from different sources, and effectively report on the pandemic in a context which is relevant to the communities they serve. The efforts resulted in November 2015 by launching a reporting toolbox for journalists at <http://www.wfsj.org/hepatitis/>). This hepatitis C website is a toolbox built by journalists for journalists to expose the complex issues thwarting prevention and treatment of this disease as well as to help journalists provide strong and accurate coverage of this infectious disease.
- ELPAs President responded to an invitation to take an active role as a member of Georgian Technical Advisory Group (HepCTAG) with the purpose of advising the Ministry of Labour, Health and Social Affairs on the goals, policies and implementation strategies, while monitoring and evaluating practices of the hepatitis C elimination programme. In April 2015, Georgia launched the hepatitis C elimination programme and has 3,000 people on treatment; Georgia is scaling up its capacity to meet high demand and is developing a comprehensive plan with specific goals and activities.







## Visiting ELPA members

Having in mind our members' needs and the importance of onsite meetings in the home countries when members have a chance to present their work, endeavors, problems and challenges as well as achievements, the ELPA President visited following members in 2015:

- Hep Help Klub in Bratislava, Slovakia accompanied by CEO
- Hronos, in Serbia accompanied by Policy director
- Star of hope was visited in Poland by CEO
- Slovenia Hep ELPA's newest member was visited by President for the occasion of WHD as already mentioned above and
- VIMOR, Hungary welcomed ELPA President on the occasion of its AGM in October



**10 Years of Advocating for Liver Health 2005-2015**



# 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 for making ELPA's vision a reality. All liver patients should be diagnosed in time, be treated with respect, and have equal access to the best standards of medical care, regardless of origin, lifestyle and type of liver disease. Our ultimate goal is a world without liver diseases.

**In 2015 ELPA's work was carried out by:**



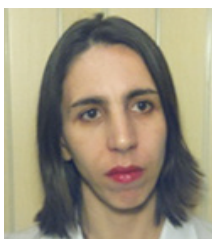
**Tatjana Reic**  
President



**Ivan Gardini**  
Vice President



**Angelika Widhalm**  
Treasurer



**Marinela Debu**  
Board member



**Milan Mishkovikj**  
Board member



**Robert Mitchell-Thain**  
Board member



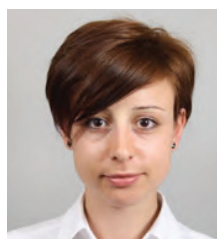
**Nadine Piorkowsky**  
Honorary Board member



**Margaret Walker**



**Achim Kautz**



**Lilyana Chavdarova**



**Nathalie Krone-Seywald**

## Financial Accounting and Transparency

The ELPA accounts are finalised in time for approval at the Annual General Meeting which is held in April of each year. The 2015 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 2015) will be posted online as soon as it is available at <http://www.elpa-info.org/finance-and-transparency.htm>

## Acknowledgements

**In 2015 ELPA received restricted and unrestricted grants as well as, in some cases, in-kind support, from the following companies:**



Bristol-Myers Squibb



GILEAD



MSD



**ELPA is also grateful to the European Association for the Study of the Liver (EASL) for its support over the years.**

**Finally, ELPA is thankful to the many ELPA members and volunteers that have helped us accomplish our goals in 2015.v**

