

ELPA

European Liver
Patients Association



10 Years of Advocating for Liver Health

Annual Report 2014

ELPA-European Liver Patients Association
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Table of contents

INTRODUCTION	3
ELPA MEMBERS	5
OUR WORK IN 2014	6
Documents and Reports Involvement and active role in other EU and global constituencies	
TREATMENT ACCESS	7
Roadmap for the care of HCV patients in 2020 Training in Liver Cancer	
TARGETED SCREENING ACTIVITIES	9
Call to improve diagnosis and access to treatments Challenges of Timely Testing and Care The First European Conference on Hepatitis C and Drug Use	
PREVENTION OF LIVER DISEASE	10
Proud to be part of the historic «Call to Action – to Scale-Up Global Hepatitis Response» Tackling alcohol related harm requires better actions Eradicating Hepatitis C from Europe – Dream or reality? Awareness Week on Alcohol Related Harm (AWARH)	
REDUCE STIGMATISATION OF LIVER PATIENTS	12
WORKING WITH OUR MEMBERS	12
WORLD HEPATITIS DAY 2014- OUR MEMBERS' ACTIVITIES	12
ELPA SCIENTIFIC COMMITTEE	14
ELPA GOVERNING BOARD AND SECRETARIAT	15
FINANCIAL ACCOUTING AND TRANSPARENCY	16
ACKNOWLEDGEMENTS	16

Liver means Life

Introduction

Dear friends and colleagues,

It was just over 10 years ago that 13 liver patient groups, from 10 countries, met to share their experiences of liver disease and set about creating a new association, which on 14th April 2005 was formally launched in Paris as ELPA, the European Liver Patients Association.

ELPA has now grown into a strong umbrella organisation with 34 members representing 26 countries in Europe and the Mediterranean basin, all working together with a common aim: **“to promote the interests of people with liver disease”**.

It is an exciting time for ELPA because there is renewed focus and interest in the powerhouse that is the liver whose work is so silent yet so vital. The fact that the liver can be compromised for years, if not decades, before gradually becoming more and more damaged highlights the importance of timely diagnosis. Having a proper diagnosis for people whose liver might be compromised is crucial as effective treatments exist already, and more are in development.

At the same time, this is also a very frustrating time for us as Europe still lacks a comprehensive framework on liver disease. Diagnosis is still occurring too late for far too many people, and in these times of austerity, access to new treatments is limited due to reduced health budgets and limited understanding on the longer term benefits, not only health-wise but also economic and social, of tackling this silent pandemic sooner rather than later.

In 2014, ELPA continued to build relationships with professional bodies, the European Parliament and national governments and focussed its activities around the 4 key messages which support our strategy to ask for improved screening, treatment and care for liver patients:

- Prevention of liver disease as key to ensuring future generations are not affected
- Screening activities are the only way to understand and tackle the epidemic
- Increased treatment rates with the latest medications available are a human right
- Reduced stigmatization of liver patients enables prevention and care to be effective

ELPA



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As the president of ELPA, and a sufferer of liver disease myself, I am proud of our achievements in 2014 and I wish to thank all those involved in our success in promoting the interests of those living with, and affected by, liver conditions. Building on the momentum we achieved last year, I am already looking forward to 2015 and establishing our new headquarters in Brussels, our first “bricks and mortar” Secretariat, to launching the first module of ELPA University, a programme for liver health and advocacy which combines both theoretical learning and skills based training, and to leading a group of committed health advocates in collaborating to make the 3rd Awareness Week on Alcohol Related Harm as successful as the 2014 edition.

Needless to say, the work on viral hepatitis is far from over and we must continue to call for equitable access to diagnosis and treatment. We also look forward to strengthening the work we have started in rare diseases, with our member organisations Hepatitis Aid Austria and PBC Foundation leading on those endeavours, and at what needs to be done to raise awareness of NAFLD, which is very much a growing concern.

As well as thanking my fellow Board members and the staff of our Secretariat, I thank all stakeholders we collaborate with. I look forward to working with you all in 2015 as we build on ELPA’s achievements of the last 10 years and continue to work on preventing others from becoming chronically ill with liver disease!



**Tatjana Reic,
ELPA President**

ELPA Members in 2014

At its Annual General Meeting, in London, in April 2014, the ELPA membership welcomed 4 new members: National Association of Infectious Liver Patients (Hungary), Hetz – the Israeli Association for the Health of the Liver (Israel), National Federation of Patients and Liver Transplanted (Spain) Liver4Life (UK). This brought the total number of ELPA members to 34, representing more than 100,000 liver patients.

**"34 members
from 26 countries,
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100,000 liver
patients"**



Austria	Hepatitis Aid Austria (HAA)
Belgium	Vlaams Hepatitis Contactpunt (VHC)
Bosnia & Herzegovina	The Chronic Viral Hepatitis Patients Association "B18"
Bulgaria	National Association for Fighting Hepatitis – Hepasist HepActive
Croatia	CATIH „Hepatos"
Egypt	Association of Liver Patients Care (ALPC)
Finland	The Finnish Kidney and Liver Association
France	Fédération SOS hépatites
Germany	Deutsche Leberhilfe e.V. Deutsches Hepatitis C Forum e.V.
Greece	Hellenic Liver Patient Association "Prometheus"
Hungary	National Association of Infectious Liver Patients (VIMOR)
Italy	Associazione EPAC Onlus
Israel	Hetz – Israeli Association for the Health of the Liver
Lithuania	Infectious Diseases Patients Association LIDPA
Macedonia	Association for health education, prevention and better treatment-HEPTA HEPAR CENTAR – Bitola
Netherlands	Nederlandse Leverpatiënten Vereniging (NLV)
Poland	Star of Hope Foundation
Portugal	SOS Hépatites Portugal
Romania	Asociația Sano-Hep România Asociația Pacienților cu Afecțiuni Hepatice din România APAH-RO
Serbia	Association for helping patients with chronic viral hepatitis HRONOS
Slovakia	HEP HELP KLUB
Spain	Catalan Association of Hepatitis Patients (ASSCAT) National Federation of Liver Patients and Transplanted (FNETH)
Sweden	Riksföreningen Hepatit C (RHC)
Turkey	HEPYAŞAM – Hepatitis Life Patients' Association
United Kingdom	The British Liver Trust The Hepatitis C Trust Liver4Life PBC Foundation
Ukraine	NGO Stop Hepatitis

Table 1: ELPA members as at December 2014

Our Work in 2014

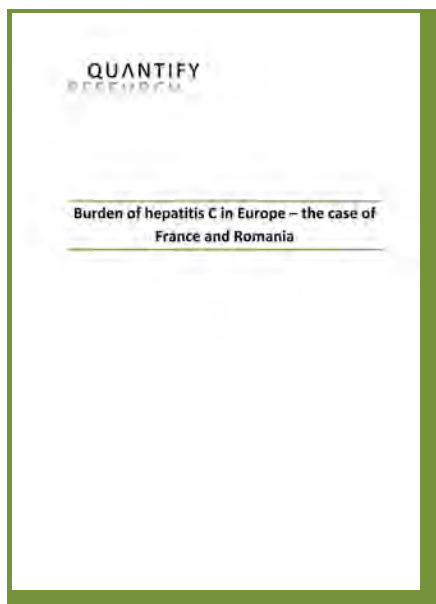
Documents and Reports

Our Manifesto “*Liver Means Life*”. The Manifesto was on policy measures against chronic liver disease 2014–2019 and provided a chance to brief candidates for the European Parliament elections and for the new European Commission on the issues and measures which urgently need to be taken to preempt the expected peak of liver disease in 2020–2025 and avert the growing burden on the health systems.

The Burden of hepatitis C in Europe – the case of France and Romania is a report commissioned by ELPA which outlines the current and future burden of hepatitis C reviewing both epidemiological and economic aspects of the disease.



The Manifesto "Liver means Life"



Burden of Hepatitis C in Europe – The case of France and Romania

Patient leaflet on primary liver cancer: provides general educational information with topics including liver cancer and its causes, symptoms, prevention and treatment, living and coping with HCC. The leaflet was prepared by ELPA and reviewed by The European Association for the Study of the Liver (EASL), The British Liver Trust and The International Liver Cancer Association (ILCA).

Involvement and active role in other EU and global constituencies

The ELPA President is a permanent member of the Board of Advisors of the Viral Hepatitis Prevention Board (VHPB) and attended one meeting in 2014, in Brazil, in March. The meeting was jointly organised with the Brazilian Ministry of Health, the Brazilian Society of Hepatology, the Pan-American Health Organisation (PAHO) and VHPB. The topic of the meeting was “Prevention and Control of Viral Hepatitis in Brazil and Latin-America”.

The second VHPB meeting of 2014 was on “Two decades of the VHPB: Achievements, Impact and remaining Challenges in Prevention and Control of Viral Hepatitis”. It was held in Antwerp and ELPA was represented by its Policy Director Achim Kautz and Board Member Hilje Logtenberg.

As a member of the WHO Hepatitis Civil Society Reference Group the ELPA President has had the opportunity to be part of the discussions, and provide input to the global response to viral hepatitis.

Treatment Access

In 2014, ELPA focussed on the need to provide new antiviral drugs at a cost which is affordable to patients.

In January our president Mrs. Tatjana Reic, speaking at a members meeting, welcomed the scientific advances of recent years but noted that drugs are only effective if available and used.

Mrs. Reic highlighted the situation that **“If the majority of HCV patients cannot access novel treatments then their existence has no impact on the severity of the growing epidemic of Hepatitis C”**.

In March, ELPA took part in a workshop titled “The Georgia Hepatitis C Control Plan: modelling for hepatitis C elimination”, that was held at the NCDC Conference Hall in Tbilisi, Georgia.

In July, ELPA joined other NGO's in a Call to EU Ministers of Health and CEO's of a number of pharmaceutical companies regarding Universal Access to Curative Hepatitis C Treatment in the EU and beyond. The communication highlighted the burden of the disease and stated **“Europeans, are facing a complete limitation, or no access at all, of state of the art treatment in our countries ... Negotiations between the EU governments and the pharmaceutical industry should involve the community”**.

***ELPA focussed
on the need to provide
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affordable to patients***

Throughout the first half of 2014, ELPA focused on raising the awareness of the Italian Ministry of Health during the Italian Presidency of the European Union. As part of a concerted effort to encourage governments to discuss viral hepatitis, and in particular Hepatitis C, ELPA prepared a document outlining the scientific case for giving it the importance it deserves. We also provided Ministry staff with a policy event concept which made suggestions for focused discussion at Ministerial level.

In November, a “sit-in” was led by ELPA's Vice-President Ivan Gardini, among others, on the occasion of the Ministerial Meeting which was held in Milan, at the time of the



Milan - 2014

Italian Presidency of the European Union. At the sit-in people living with hepatitis C and their allies advocated for and demanded a clear political and public health commitment and better leadership from the European Union and the European Commission.

Later that month, also in Italy, Achim Kautz joined a Health Technology Assessment meeting which provided ELPA with the opportunity to provide input into the need for faster approval of the latest medication, of including new high risk groups into clinical trials and ensuring that approved medication has the chance of being used by those who are in urgent need.

In December, during the European Parliamentary event “Fighting Viral Hepatitis in Resource-Limited Member States” ELPA

Policy Manager Lilyana Chavdarova presented on the patient perspective, with a particular emphasis on the challenges that patients face when living in countries where healthcare resources are limited. The objectives of this EP event was to better understand the disease burden associated with viral hepatitis in resource-limited member states.

Roadmap for the care of HCV patients in 2020

Attended by ELPA's president, the HCV2020 meeting brought together a multidisciplinary group of 77 experts from across the world to share ideas and experiences and address questions on patient care in the new world of HCV treatment. The group determined the steps required to achieve high-quality care for HCV patients in 2020, and identified the priority actions needed to achieve this.

Training in Liver Cancer

Public awareness of primary liver cancer (HCC), risk factors, prevention strategies and treatment options is extremely low. Liver cancer is the second most common cause of cancer deaths, and therefore monitoring the people at risk and expanding access to new therapies is increasingly important. To address this situation ELPA organized the first 'Training in Liver Cancer'. The goal of the three day training was to deliver to ELPA members the latest information with respect to the screening and treatment developments in HCC, as well as to increase the awareness and skills of patient advocates and provide them with tools for different advocacy strategies and implementation.

Designed for patient advocates, and leaders of ELPA member organization who are active in the late/end stage of liver disease, ELPA was pleased to welcome a total of 18 delegates from 14 countries to the 3-day event.

During the course, ELPA Members gained a unique opportunity to discuss administrative and political challenges with government officials at both national and European levels. Austrian MEP Karin Kadenbach attended the event and shared with ELPA members her experiences of working with patient advocates at EU level. Ms Kadenbach also gave the meeting participants some hints and tips to enable them to maximize the opportunities for engaging with policy makers at EU level via the work they carry out at national level.

Feedback

Feedback from the course showed wide satisfaction and ELPA looks forward to continuing and expanding the training course programme in the future.



ELPA - Training in Liver Cancer - 2014

Targeted screening activities

Call to improve diagnosis and access to treatments

At the beginning of 2014, as part of ELPA's ongoing commitment to work with, and influence liver disease health policies, ELPA did its best to support the initiative of a number of Romanian MEPs, including Christian Busoi (Chair of the Friends of the Liver Interest Group) in trying to obtain the necessary number of signatures for a declaration on Hepatitis B and C which was submitted to the European Parliament. Unfortunately the required number of signatures was not achieved but this initiative highlighted the increased awareness amongst MEPs of the importance of this issue.

A few months later, our President, Tatjana Reic, reinforced the call to improve diagnosis of liver disease and for better access to treatments, during her speech at the opening ceremony of the International Liver Congress in April. She explained that treatments that had not been imagined decades ago are now possible, but most people with liver conditions unfortunately do not know they are affected due to its asymptomatic nature. Due to a reduction in healthcare budgets, diagnosis programmes and access to treatment are not standardised across the EU. Ms. Reic called for liver enzyme tests to be included in reimbursed regular health checks.

In June, ELPA also supported a high-level meeting in Greece where austerity programs have had a negative effect on public health outcomes. **"The Economic Crisis and healthcare – ensuring access to public health services: The case of hepatitis B and C"** meeting in Athens brought together

national and international associations of healthcare experts, including World Bank specialists, doctors, civil society leaders and politicians.

Participants identified barriers and challenges and sought solutions to improve access to care and treatment of hepatitis B and hepatitis C, even in countries where austerity programmes are in place.

Challenges of Timely Testing and Care

The HepHIV 2014 Conference: HIV and Viral Hepatitis brought together for the first time, stakeholders from the fields of viral hepatitis and HIV/AIDS. ELPA was strongly represented and highly visible in its support as a member of the conference steering committee, and ELPA's Policy Manager Lilyana Chavdarova presented the Euro Hepatitis Care Index 2012. In addition to active participation in discussions and presentations, ELPA also authored a position paper titled *Improved hepatitis C screening and treatment in people who inject drugs should be a priority in Europe*"

which was published in the accompanying BMC Infectious Disease supplement.

The First European Conference on Hepatitis C and Drug Use.

With the aim to develop a pathway for effective health responses and to open treatment for those who need it, this conference brought together drug user community representatives, harm reduction experts, health care professionals, pharmaceutical companies, researchers and policy makers.



ELPA - ILCTM 2014

ELPA and its members
are dedicated to
multi-level initiatives
involving EU and national policymakers,
liver specialists associations and
public health experts



ELPA's Policy Director, Achim Kautz presented the section on **'Effective Targeted HCV Strategies and Action Plans'**, an area of work which ELPA is very much involved in as it has provided support for our member associations in Romania, Croatia, Bulgaria, Germany, Serbia and Greece as they work to encouraging their governments to use strong strategies and action plans to combat this silent pandemic.

Highlight

A highlight of the conference was the presentation of the **'Berlin Declaration'**, The Declaration has been hailed **"a pressing call to national and European policy makers, to ensure better access and quality of hepatitis treatment for the most marginalized groups"**.

Prevention of Liver Disease

Proud to be part of the historic **'Call to Action – To Scale up Global Hepatitis Response'**

The meeting of Global Partners convened by the World Health Organisation in Geneva, at which ELPA was represented by its President, Policy Director and CEO, 'united stakeholders as a global platform for better communication and collaboration to support a public-health, rights-based approach to viral hepatitis'.

The resulting 'Call to Action' presses the global community for immediate and concerted action to increase access to prevention, diagnosis and treatment of viral hepatitis. It highlights much needed action points under the titles of:

- Advocacy and awareness
- Knowledge and evidence
- Prevention of transmission
- Screening, care and treatment

Tackling alcohol related harm requires better actions

Throughout 2014, ELPA joined the public health community in encouraging the European Parliament to issue resolution calling for a new EU Alcohol Strategy. Many months of concerted and coordinated efforts have resulted in a proposed Resolution which will be discussed by the European Parliament at the end of May 2015.

ELPA supported and continues to support the Eurocare (European Alcohol Policy Alliance) **"Call for a Comprehensive Alcohol Policy Strategy in the European Union"**. The Call asks the new EU Political Leaders to develop an updated EU Alcohol Strategy that **"should lay out a longer term framework for sustainable action at the EU level and seek to support and complement comprehensive national alcohol strategies by focusing on policy areas where the EU mandate can add value"**.

In 2014, ELPA applied for and obtained membership of the Commission's European Alcohol and Health Forum. The overall objective of the EAHF is to provide a common platform for all interested stakeholders at EU level that pledge to step up actions relevant to reducing alcohol-related harm.

Eradicating Hepatitis C from Europe – Dream or reality?

A symposium organised by ELPA, during the International Liver Congress in London, brought together specialist doctors, EU policy-makers and patient representatives to discuss how well the new treatments performed in daily practice, and to reflect on this era of new optimism where hope is offered to patients who used to be difficult or impossible to treat. The panel also discussed side effects, the potential to reach cure rates above 90% outside the clinical trial setting and new practical issues encountered, even with new and vastly improved treatments. With over 300 participants in attendance, ELPA's 2014 symposium was by far the most successful so far.

Awareness Week on Alcohol Related Harm (AWARH)



Awareness Week on
Alcohol Related Harm
24 - 28 November 2014

www.awarh.eu

The **Awareness Week on Alcohol Related Harm (AWARH)** is an initiative of ELPA, Eurocare, EASL, EBC, EUFAMI, UEG and Lundbeck.

AWARH's objective is to call policy makers to commit to an integrated approach to alcohol policies, including improved healthcare services that are adequately reflected and budgeted for.

The theme for the second Awareness Week on Alcohol Related Harm, which took place in late November, was **The EU Alcohol Strategy: Act Now!**

ELPA hosted the Secretariat for AWARH 2014 and delivered outstanding communication

Key messages of AWARH 14 were

- The EU Alcohol Strategy must be renewed
- Alcohol is linked to more than 60 chronic diseases and is harmful to society from a socio-economic standpoint
- Integrated alcohol policies including prevention, early diagnosis, access to treatment and better services provision are needed
- More funding is needed to provide for cost-effective holistic alcohol policies



materials including newsletters and updates, which reached over 1200 recipients, a website (www.awarh.eu), social media outreach and four infographics. In addition, ELPA was responsible for organizing two events, one of which took place at the European Parliament in Strasbourg, was hosted by Cristian Busoi and Nessa Childers MEPs, and had as its highlight the participation of Commissioner for Health Vytenis Andriukaitis.



AWARH - European Parliament in Strasbourg - 2014



Markus Peck (EASL) - Tatjana Reic (ELPA)

Reduce stigmatisation of liver patients

HCV and Your Body – Two day training

There is a huge variation in support networks for the 150-200 million people worldwide who are infected with chronic HCV and living with the many medical, social and emotional difficulties associated with the disease. Gilead Sciences and ELPA identified the need to bring together the European HCV community and developed the “HCV and Your Body” programme as a platform to share ideas, best practices and help invoke change in communities.

Medical Impacts of HCV

Delegates were given a broad overview of conditions and extra hepatic manifestations associated with HCV. Delegates were asked to consider the clinical impacts and how these could be addressed to help patients.

Emotional impacts of HCV

A personal account was given, of the emotional difficulties and challenges faced during HCV diagnosis and treatment. This provided a starting point for engaging and interesting discussions.

Social Impacts of HCV

This session explored the many social difficulties sometimes experienced by patients e.g. stigma, homelessness, unemployment, and HCV in prisons. Delegates considered social difficulties experienced in their home countries and the initiatives in place to support HCV patients.

Feedback

Feedback from the sessions was positive and we received many suggestions for topics of future meetings, which will be developed in 2015.

Commission requests for feedback/consultations:

In 2014, ELPA provided feedback to the European Commission/Parliament on the following topics:

- Chronic Disease Consultation
- European Code Against Cancer revision
- Preliminary opinion of the Expert Panel on Effective Ways of Investing in Health (EXPH) on a “future EU Agenda on quality of health care with a special emphasis on patient safety”.

Working with our Members

As part of ELPA’s strategy to engage more closely with its members a number of working visits were undertaken in 2014. These visits included one-on-one meetings with our members in Greece, Italy, Austria, Germany, the United Kingdom, Serbia, Finland, Sweden and Slovakia. Discussions during these different meetings included EU Presidencies, membership engagement, national initiatives and possible ELPA involvement, strategic planning, etc.

World Hepatitis Day (WHD) 2014 – Our Members’ Activities

World Hepatitis Day took place on the 28th July, and ELPA was delighted with the support given to this important event by our members, and the resulting increase in awareness, diagnosis, and treatment.

Croatia

Croatian Association of treated and ill from Hepatitis (CATIH Hepatos) and Croatian Alliance of Hepatitis Patient Associations informed ELPA that the excitement during

the build up to WHD 2014 in Croatia was significantly dampened by the decision of the Croatian Health Insurance Fund to reduce funding for hepatitis treatment out of the state budget and move this to individual hospital responsibility. This meant that due to the poor financial situation of many hospitals, access to treatment for many hepatitis patients was limited. Activities started at the end of June 2014, with an advocacy letter, which was issued to Members of Parliament, media and other stakeholders. This was followed up by a meeting with the assistant to the Minister of Health, to discuss problems facing Hepatitis patients in Croatia. The “Public Policy Analysis in the domain of viral hepatitis in the Republic of Croatia” document which details priorities for further work and development of a national strategy was discussed further at two meetings held in Zagreb. On the occasion of the WHD, Dr. Ivo Josipović, President of the Republic of Croatia, received ELPA President Tatjana Reic and representatives from CATIH HEPATOS. Discussions focused on the absence of a national strategy for hepatitis in Croatia and highlighted the insufficient funding for treatment and the lack of prevention programs. Also highlighted were the reduction in access to treatment for chronic hepatitis patients as consequences of the new therapy protocol.

Macedonia

Hepar Centar-Bitola held various activities to improve the understanding of hepatitis related issues and trigger public support to address the disease at national level. Activities ranged from large-scale free medical examinations for Hepatitis C, to the distribution of a range of educational materials and free condoms in popular tourist destinations. The campaign was supported by celebrities and culminated in a music concert held in the centre of Bitola. Media coverage was extensive and spanned across print media, television and radio broadcasts.

Poland

The WHD event in Poland consisted of several targeted activities: a convention of organisations related to the Hepatitis Coalition, a hepatitis information bus which moved through Warsaw and gave advice and information to visitors, and free HCV check-ups in 5 major cities. The activities resulted in significant press coverage and social media activity, which reached nearly 7 million people.

Egypt

Various activities took place at the ELRIAH waiting hall with an audience of patients, guests, children and employees, and included a play which raised awareness of hepatitis transmission, various films, competitions with prizes, a puppet show for children, and free tests for HBV and HCV.

Romania

Activities took place in 13 cities across the country and under the slogan ‘**Stop Hepatitis! Be aware of A, B, C and D**’. Over 25,000 leaflets were distributed to raise awareness about the transmission of hepatitis and how the virus can be detected. 1000 blue and white balloons were also released to attract attention and invite people to think twice about the risks of infection and how they expose themselves to risk.

Austria

Over 7000 participants at the WHD event wrote personal messages for better understanding, which were then attached to blue and white balloons and released into the sky above Vienna. Attending the event were representatives of the Hepatitis Help Organization Austria, physicians, and the Federal Minister Labor, Social Affairs and Consumer Protection, Rudolf Hundstorfer.

Hungary

Across 15 cities hepatologists and members of patient associations helped to raise awareness of hepatitis infections, treatment opportunities and to fight against negative

discrimination. Information leaflets and patient questionnaires were distributed, and those who ranked at high risk in the questionnaire were invited to be tested, and informed of treatment options. A national media campaign was organized, with outreach through print, television and social media.

Greece

The Hellenic Liver Patient Association “Prometheus” organized several events to boost awareness and bring the topic of viral hepatitis closer to the public and policy makers.

Prometheus developed an awareness video which highlighted the lack of understanding and awareness of Greeks of viral hepatitis. Screening for hepatitis C and distribution of information materials was conducted in Marousi, Athens Greece. This initiative was maximised with the use of social media and a follow up press release by the municipality of Marousi. A policy round table was organized with over 100 people in attendance. Government representatives met with patient advocates from the region and had an open discussion on the deficiencies in health care and patient needs. Mr. Achim Kautz, ELPA Policy Director, provided valuable insights from the wider European perspective.

Finally, the Hellenic Scientific Association for the Study of the Liver organised a press conference to which “Prometheus” was invited. The press event aimed to the stress on urgency of addressing the threat of viral hepatitis in Greece.

Germany

On World Hepatitis Day, Deutsche Leberhilfe e.V. launched an online e-learning programme for hepatitis C patients (<http://www.elearning-hcv.de>) and accompanied the day with press releases, media interviews and their German WHD website www.welthepatitistag.info. Thanks to the arrival of new hepatitis C medicines, World Hepatitis Day 2014 received a vast amount of coverage in German television, print and online press.”

ELPA Scientific Committee

The ELPA Scientific Committee has a specific role within the Association to ensure that ELPA is involved at the forefront of scientific developments concerning liver disease.

In 2014, it worked with the European Medicines Agency (EMA) to review a clinical study and over 15 leaflets. ELPA also had representatives at the EMA’s Workshop on Viral safety of plasma-derived medicinal products with respect to the hepatitis E virus. The purpose of this workshop was to gather further information on the safety of plasma-derived medicinal products and provide the basis for deciding what further action may be needed with respect to HEV. ELPA also attended the European Medicines Agency Human Scientific Committees’ Working Party with Patients’ and Consumers’ Organizations (PCWP) November meeting.

The Scientific Committee helped develop the agenda and discussion points for an Advisory Board Meeting, where the main topic of discussion was current and upcoming treatment options and where representatives of Bristol Myers Squibb, Gilead, and Janssen were invited to present to the ELPA membership.

The Scientific Committee members also reviewed project proposals for Horizon 2020 in which ELPA was invited to collaborate. Of the four project proposals we were asked to be involved in, one is currently at Stage II of the application process, two did not make it past Stage I and a third is in early development. ELPA hopes that as its Secretariat capacity continues to increase it will be in better position to be more involved in different project proposals.

Finally, the Scientific Committee prepared and coordinated the ELPA Symposium which takes place each year at the International Liver Congress. In 2014, the theme of the Symposium was **“Eradicating Hepatitis C from Europe – Dream or reality?”**. The symposium was moderated by Professor Graham Foster and included presentations by Dr Andrew Amato-Gauci, Prof. Massimo Colombo, Prof. Dr Adriana Vince, Dr Natasha Martin, Prof. Thomas Berg, Ingo van Thiel and Ivan Gardini.

ELPA Governing board and Secretariat

The European Liver Patients Association (ELPA) is a non-profit association for viral hepatitis and other liver diseases. ELPA is run by a Governing Board which is elected by its membership at the Annual General Meeting. In 2014, ELPA established a virtual Secretariat with CEO at the helm.

The Board and the Secretariat work towards making ELPA's vision a reality; that all liver patients are diagnosed in time, are 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.

In 2014, ELPA's work was carried out by:

Governing Board

Tatjana Reic
President

Ivan Gardini
Vice President

Hilje Logtenberg-van der Grient
Treasurer

Angelika Widhalm
Member of the Steering Committee

Stanimir Hasurdjiev
Board Member

Nadine Piorkowsky
Honorary Board Member

Scientific Committee

Ingo Van Thiel
Ivan Gardini
Hilje Logtenberg-van der Grient

Secretariat

Margaret Walker
CEO

Achim Kautz
Policy Director

Lilyana Chavdarova
Policy Manager

Nathalie Krone-Seywald
Event Manager



Tatjana Reic



Ivan Gardini



Hilje Logtenberg-
van der Grient



Angelika Widhalm



Stanimir Hasurdjiev



Nadine Piorkowsky



Ingo Van Thiel



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 2014 final accounts will only be available on 25th April 2015 and are therefore not included in

this report. Full information (ELPA Balance Sheet, Accounts and Funding Sources 2014) will be posted online as soon as available at <http://www.elpa-info.org/finances.htm>

Acknowledgements

In 2014 ELPA received restricted and unrestricted grants as well as, in some cases, in-kind support, from the following companies:



We are also grateful to the European Association for the Study of the Liver (EASL) for its support over the years. The fact that in 2015 we are celebrating the 50th annual meeting of EASL, 30 years of the Journal of Hepatology and the 10 year anniversary of ELPA is a clear indication of the importance of the work our respective organisations carry out on behalf of the estimated 29 million EU citizens suffering from a chronic liver condition.

Finally, we are very thankful to the many ELPA members and volunteers that have helped us accomplish our goals in 2014.

We look forward to ongoing collaborations!

