

ELPA

Quartal News Report

April – June 2017



ELPA

European Liver
Patients' Association

April – June 2017 Highlights:

1. ELPA activities at ILC 2017
2. 1st European NASH-NAFLD Policy Summit
3. Membership in Civil Society Forum
4. Launch of ACHIEVE coalition
5. New ELPA website www.elpa.eu
6. Launching documentary film *From hell to Hope*



ELPA activities at ILC 2017



This year's EASL week was held in Amsterdam from 18th to 23rd of April. Just as in previous years, ELPA conducted several activities during one of the most important liver events in Europe, including the speech ELPA President **Tatjana Reic** has delivered at the Opening ceremony.

On that occasion she has sent out several meaningful messages to the audience comprised of esteemed clinicians, patient advocates, industry and other stakeholders.

Follow [this](#) link to hear ELPA President giving speech at the ILC 2017.



ELPA Symposium



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



Prof. Anna S. Lok, President of AASLD



Ingo Van Thiel



Marko Korenjak and Tatjana Reic



Prof. Pere Gines

One prediction we are sure about

European Liver Patients Association
ELPA



Hepatology after hepatitis C will not get boring!



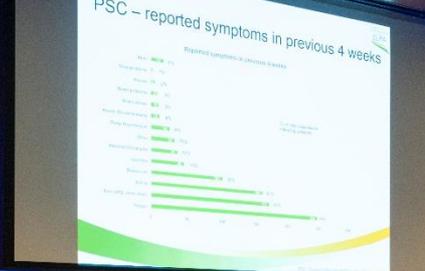
Restrictions on access to direct-acting antivirals for HCV treatment

Are there any restrictions on access to direct-acting antivirals for the treatment of HCV in your country?

Yes (12)
No (1)
Unsure/Unavailable



PSC – reported symptoms in previous 4 weeks



Tajana Ren



Annual General Meeting

Annual General Meeting

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

Annual Report

Annual Report for 2016 was released our activities at ILC 2017 and disseminated to all ELPA AGM and ELPA Symposium participants. In case you missed to have a look at it, please follow [this](#) link and learn more about our activities back in 2016.



Leaving a trace.
ELPA Annual Report
2016

The Hepatitis C Community Summit

On April 19th ELPA members and Governance have participated in The Hepatitis C Community Summit during the EASL annual congress in Amsterdam. Members from Sweden, Turkey, Macedonia, Romania and Slovenia gave an overview on the Hep-CORE survey conducted in their country, and encouraged the discussion on the current situation on the implementation of hepatitis B and C policy recommendations in other European countries.

In addition to this highlights, ELPA Governing Board has held its 2nd Board meeting in this year as well as the meeting with EASL Governing Board, while executive team has held numerous meetings with industry and other stakeholders in order to further strengthen ELPA's position.

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

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



1st NAFLD - NASH EU Policy Summit

NAFLD – NASH Summit in EU Parliament on May 31st

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

Follow [this](#) link to learn more about the summit and to download speakers' presentations.

ELPA at Civil Society Forum

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

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

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

About Civil Society Forum and Think thank group

The Directorate General Health and Food Safety ('DG SANTE') of the European Commission has set up a group of experts called the EU HIV/AIDS, VIRAL HEPATITIS AND TUBERCULOSIS Civil Society Forum ("CSF"). The aim of the CSF is to be a forum for informal consultation of the EU HIV/AIDS Think Tank (Think tank is an expert group comprising representatives of national health authorities in EU Member States and selected neighboring countries) and Commission services with Civil Society; to facilitate the participation of NGOs and networks, including those representing people living with HIV/AIDS, viral hepatitis (B and C) and tuberculosis, in European policy development and implementation, and to exchange information. The CSF meets twice per year in conjunction with the meetings of the Think Tank.

Launch of the ACHIEVE coalition





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

To learn more about the work of ACHIEVE coalition, please follow [this](#) link.

ACHIEVE coalition and Luxemburg meetings

On the 3rd and 4th of May, as part of the ACHIEVE coalition work, just before the launch, **ELPA President Tatjana Reic** and **Angelos Hatzakis** met with **John Ryan**, Director, Public Health, Country Knowledge and Crisis Management and **Jean-Luc Sion**, Policy Officer in charge of HIV/ Aids, Hepatitis and Tuberculosis at DG Health and Food Safety for the European Commission in Luxemburg.

ACHIEVE coalition brings together various range of stakeholders: patients, healthcare professionals, public health experts and risk group representatives whose aim is to bring the hepatitis elimination on the EU political agenda.



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New coalition calls on the EU to take action to eliminate viral hepatitis by 2030

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Find out more about fighting liver disease or patient-related topics, learning about the work of other international organizations, agencies and institutions.

Useful links

Following the change of ELPA logo sign, first mid of April was marked by the launch of new ELPA website www.elpa.eu as well as transfer to new e-mail addresses name.surname@elpa.eu

Change of e-mail addresses

As a continuation to our domain change **from elpa-info.org to elpa.eu**, ELPA team has changed their e-mail addresses, which you can now add to your address book. Have in mind that all the e-mails sent to elpa-info.org are being forwarded to elpa.eu and there is no chance that some of them will be lost even if you do send them to the elpa-info.org.

Below please find the list of new addresses:

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

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

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

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

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

Nadine Piorkowsky: Vice president nadine.piorkowsky@elpa.eu

Livia Alimena, Public Affairs Director: pad@elpa.eu

Lana Crnjac, Policy Officer: office@elpa.eu

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

Launch of documentary film

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

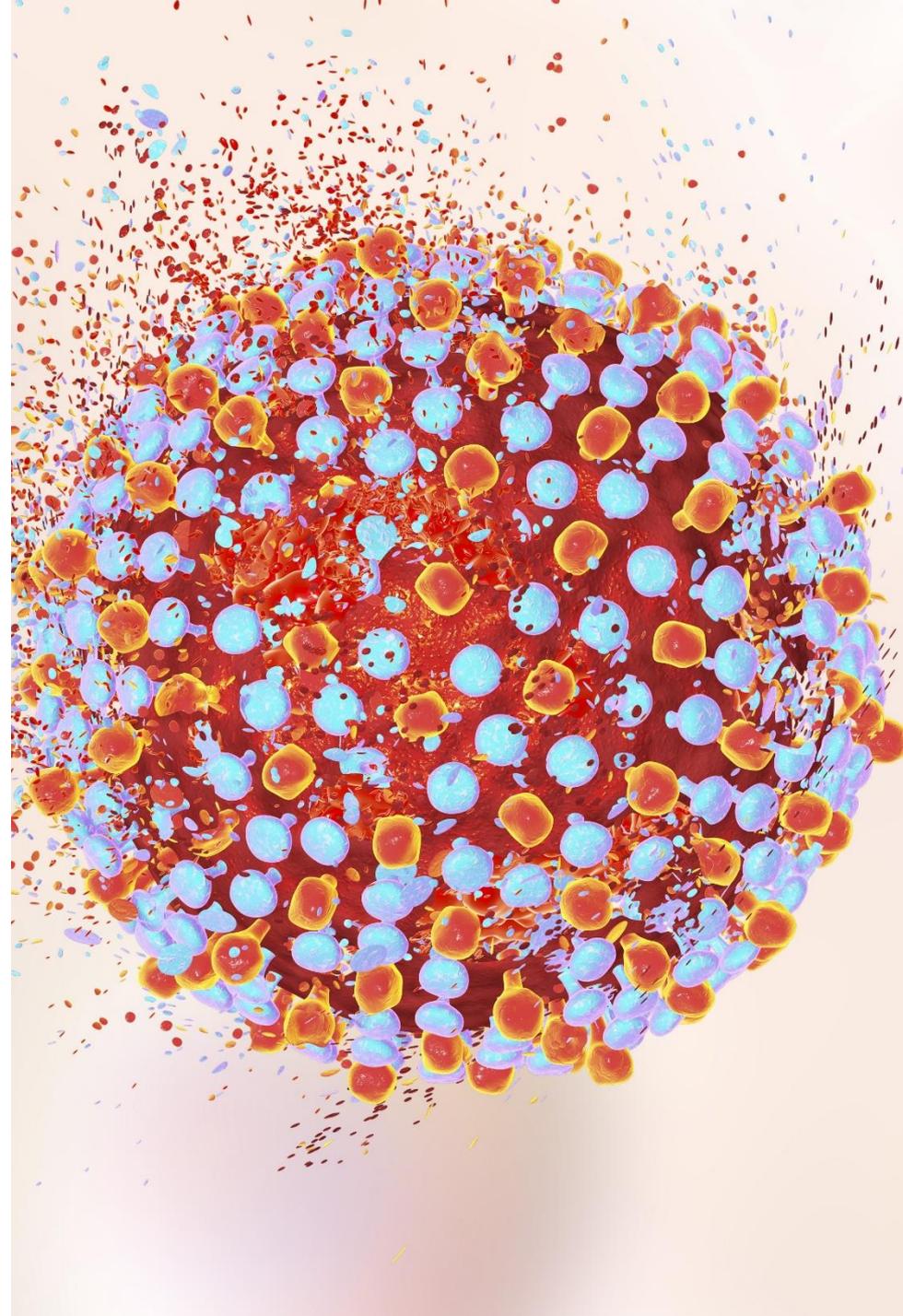
***„From Hell
to Hope“***

ELPA

In addition

ELPA's response to Cochrane study

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



European Liver Patients' Association and Norgine continuing to improve the management of Hepatic Encephalopathy

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

Hepatic encephalopathy is a significant complication of advanced chronic liver disease, and occurs in up to 40% of patients or as many as 200,000* people in Europe.

Learn more following [this](#) link.

HA-REACT meeting on financing of harm reduction service

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

EPF Annual General Meeting

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

Alcohol related activities

Alcohol Labelling meeting

On April 26th, just after the EASL week, ELPA was invited to participate on the Alcohol Labelling Meeting, organized by Eurocare as a response to European Commission's published report on alcohol labelling. The meeting served as a great possibility to exchange ideas and to consider the possibilities for cooperation. At this occasion, ELPA was represented by Policy Officer **Lana Crnjac**.

AWARH Planning Meeting

This year's AWARH kick-off meeting was held on May 17th, gathering partners like Eurocare, EASL, EUFAMI, European Brain Council, UEG and ELPA, in order to discuss AWARH 2017 campaign. Just as previous years, ELPA will participate and continue to work on raising awareness on alcohol related harm within the „Awareness Week on Alcohol Related Harm (AWARH)“, where our representative is **Lana Crnjac**.

AWARH was initiated in 2013 by a group of like-minded organisations following three roundtable meetings on an integrated approach to alcohol-related harm.



Viral Hepatitis and Your body

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

Call to action: Organ donation and transplantation Across the EU

Following initial meetings in October 2016 and January 2017, a third meeting on organ donation and transplantation across Europe was held on May 18th. In order to keep the momentum representatives from organizations such as ELPA, European kidney Health Alliance, European Kidney Patients' Association, European Federation of Allergy and Airways Diseases Patients' Associations, European COPD Coalition, Donor and Transplantation Institute discussed the ways in which they can work together to raise awareness of the importance of organ donation and transplant, both amongst policy makers as well as the general public. Meeting was attended by ELPA's Vice President **Angelika Widhalm** and Policy Officer **Lana Crnjac**. To remind you, PHA Europe decided to develop **Call to Action** to address issues such as shortage of organs, long waiting lists, high mortality, lack of awareness, understanding in the general population and, in some countries, lack of surgery facilities. Call to action is a cross-condition transversal campaign where organizations with the same problems could advocate for change together.

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

During Lisbon Hepatitis week 12-16 June, ELPA President **Tatjana Reic** has participated in ECDC (European Centre for Disease Prevention and Control) meeting of the Hepatitis B and C network from June 12-13, where she presented **“Civil Society’s expectations of ECDC’s future priorities”**. ELPA President took the opportunity to especially highlight one of the crucial issues in fighting hepatitis – lack of data measurement.

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

Participation at EATG Advisory Board meeting

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

Participation at EPKF General Assembly

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

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

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

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

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

Patient-MedTech Workshops & Conference on Nutrition, and see Updates from Members & Partners

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



New access conditions for Italian Hepatitis C patients'

Hepatitis C patients' in Italy can benefit of new access conditions. Since few months all access limitations to treat HCV patients have been abolished thanks to the co-operation of all stakeholders involved: the Italian patients organization (EpaC), the Italian drug agency (AIFA), the scientific societies and the Healthcare Minister. The stated goal is the elimination of the disease, which currently affects 350.000 patients who have been diagnosed and causes 10,000 deaths per year. The plan is to treat 240,000 patients over the next three years, taking advantage of the €500 million per year, allocated under the new budget. This amount allows 80.000 patients to be treated each year and defines 11 new criteria to establish priorities (i.e. including infected healthcare professionals, patients with HIV or HBV co-infections or even patients on a waiting list for organ transplantation or bone marrow). As Ivan Gardini (EpaC President) points out: "this is a turning point in Italian history for HCV patients. Italy belongs now to the first 10 nations in the world which granted unlimited access to the new DAAs. Our universal healthcare system is one of the most admired for its coverage and we have managed to consider its sustainability as well".

ELPA in EU projects

Project Liverhope

Liverhope, EU funded project aiming to introduce simvastatin and rifaximin as new therapy for patients with decompensated cirrhosis, which ELPA is a part of, has issued their first newsletter. To learn more about Liverhope activities, please follow [this](#) link.

Project Liverscreen

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

Project Galaxy

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

Board meetings

3rd 2017 Board meeting

ELPA Governing Board has held its 3rd meeting this year in Prague on May 10th, just a day before the Viral Hepatitis and Your Body training programme.

4th 2017 Board meeting

ELPA Governing Board has held its 4th this year's meeting in Brussels on June 10th. As always, in order to assure that all the processes are in line with ELPA strategies and members' needs, the Board discussed ongoing projects as well as financial report regularly devised for Board. Since ELPA is constantly working hard on improving work processes that will ensure better quantity and quality of deliverables, Board has made two decisions: one of decisions which will further help to boost ELPA productivity is that all Board members will continue their work as Vice Presidents in charge of some specific area of work. Following that decision Marinela Debu remains as Vice President for accounts and budget and Angelika Widhalm as Vice President in charge for networking, while Marko Korenjak acts as Vice President for coordination and development, Milan Mishkovikj as Vice President for digital presence and Robert Mitchell-Thain as Vice President for education. By that, Board members have specific areas in which they are expected to provide their expertise and, consequently, speed up the work processes. Additionally, Lana Crnjac, former Office and Communications Manager was promoted to Policy Officer. After almost one year of in depth collaboration on ELPA related issues, Lana Crnjac has accepted this promotion through which she will continue her work with ELPA on patient's advocacy.

Working groups

As announced in ELPA Strategy for 2017, describing Strategic goal 1 *Members empowerment, Action 1.2*, ELPA has established its first working group. The group will gather experts in Rare diseases and will be led by **Richard Hall** from Liver4Life. We are now working on establishing new groups which will cover specific liver condition area and are looking forward to see ELPA members taking part in it. Future steps and terms of collaboration, as well as information on Rare disease group, will be explained to all members through our weekly activities report.

Audit

As per decision taken during this years' Annual General Meeting, proposed by ELPA Governing Board, ELPA has started with a process of professional external audit. Upon its completion, ELPA Board will present the results of the audit to ELPA members.

Changes in ELPA Board

Robert Mitchell – Thain has resigned from his position in ELPA Governing Board on June 13th. Whole ELPA team would like to wish him the very best in all your future endeavours. We have no doubt he will continue to perform to his usual high standards both in his next projects and within ELPA Scientific Committee.

ELPA Governing Board will inform members on the future steps regarding this issue.

Whole ELPA team would like to wish him the very best in all future endeavors. ELPA Governing Board will inform members on the future steps regarding this issue.

ELPA's aim is to promote the interests of people with liver disease and in particular: to highlight the size of the problem; to promote awareness and prevention; to address the low profile of liver disease as compared to other areas of medicine such as heart disease; to share experience of successful initiatives; to work with professional bodies such as EASL and with the EU to ensure that treatment and care are harmonized across Europe to the highest standards.

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