



Annual Report

2020

2021

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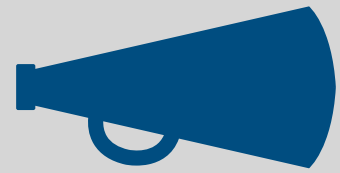
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WORD FROM THE BOARD



As we reach our second anniversary we leave behind a year greatly impacted by the COVID pandemic and the subsequent shutdowns and restrictions. In spite of this we had some positive achievements this year.

Expanding our membership network has been slow but successful with a number of new patient organizations joining LPI this year. Alongside we welcomed a new member of our Board, Silvana Lesidrenska – Chair HEPACTIVE Bulgaria- Silvana brings a wealth of expertise around hepatitis B to the board from both lived and professional experience.

Throughout this year we have successfully expanded the network of organizations that we work with, collaborating both in and out of Europe, expanding LPIs reach while ensuring that the patient voice has remained central in all our work. Focusing on our communications we have built our presence through attendance and representation at global and European conferences and on all social media channels ensuring that we are able to reach the most marginalized of populations, civil society organizations and policy makers.

As we move forward, we are mindful that while there have been many positives over the past year, we also face some unknowns, in terms of the further impacts of the COVID pandemic. We do, however, move forward with hope, and enthusiasm. We are committed to increasing our membership, strengthening the global movement of Liver patients through civil society organizations and in turn the voice of patients. 'Leave no one behind' remains the central principle of all our work.

On behalf of the Board of Directors, I look forward to another year of growth, development and enhanced partnerships.

Yours sincerely,

George Kalamitsis, Chair, Liver Patients International

WHO WE ARE



We are you. We are us.

We are patients yet to be diagnosed.

We are patients living with liver diseases.

We are the embodiment of change: to improve patients' access to timely diagnosis, appropriate healthcare, to the best possible quality of voice and a voice in the decision-making process.

We are transparency. We are equity. We are mutual respect. We are integrity.

We are: Liver Patients International

THE BOARD OF DIRECTORS



Chair: George Kalamitsis

George is a founding member and Chair of Hellenic Liver Patients Association "Prometheus" since 2012 and a founding member of Greek Patients Association. He is engaged in Health Policy, specialized in the public health sector. His work is related to providing support to people living with Viral Hepatitis, advocating for their rights and providing evidence-based policy actions. Recently, he was assigned as Member of the Central Board of Health (2019) and as President of the Committee Protecting the Rights of Recipients of Health Services (Greek Ministry of Health 2017). He has been working extensively with multiple stakeholders, focusing on patients' rights as well as building communication channels with organizations and stakeholders, on a National and International level.



Vice-Chair: Robert Mitchell-Thain

Robert is the Director of Pediatric and Rare Liver Disease, and of Patient Insights, at Global Liver Institute, GLI, and until recently he worked as the Head of Education and Development at the PBC Foundation: a UK-based support and advocacy charity that supports those affected by PBC in over 75 countries.

Robert has presented to and on behalf of liver patients in USA, Canada, Russia, Israel, Japan, and China as well as many countries in Europe. He has co authored abstracts and clinical guidelines, and lead-authored abstracts, accepted by bodies such as EASL and AASLD, highlighting the patient experience. He is on a number of committees representing the patient voice.

THE BOARD OF DIRECTORS



Treasurer: José Willemse

José is the executive director of the Dutch Liver Patients Association and very active in the national and international expert concerning several liver diseases. She is also a board member in the ERN RARE LIVER. She is experienced for approximately 25 years in the field of patients' associations.



Deputy Treasurer: Rachel Halford

Rachel is CEO of The Hepatitis C Trust, a UK National patient led and run organization that provides information, support and advocacy services for people affected by hepatitis C. Currently a staff team of 160 people, 60 paid staff many of whom deliver Peer Support services in both the community and prisons and 100 volunteer peers. Rachel has over 20 years' experience of working with people at high-risk of viral hepatitis, and liver disease generally – the homeless, prisoners, substance users and migrants and is currently the Executive Board Member for the European Region for the World Hepatitis Alliance.



BoD member: Silvana Lesidrenska

Silvana is the Chairperson of the Managing Board (2012 - ongoing) of HepActive Patients' Association in Sofia, Bulgaria. Founded in 2009 by a group of patients, HepActive's main goal is to provide information and assistance to anyone affected by viral hepatitis. As a patient-focused, non-governmental organization, HepActive offers a wide range of support services including free and anonymous rapid hepatitis testing, counseling and linkage to care. In addition to that, HepActive has been running an online patients' forum with 2700 members (since 2006), a website with medical articles (since 2009), where people can find support and reliable information.

OUR OBJECTIVES



Liver Patients International, strives to achieve its goals, breaking barriers and placing the patient and their voice at the center of all that we do. It is our core belief that through working together, we can ensure that all our members have access to the resources, tools and support that will enable them to influence policy makers and ensure the best possible outcomes for their members.

Trust and transparency are core to our values and key in securing and maintaining successful relationships with both our members and all stakeholders.

Working with integrity is paramount: LPI's Board of Directors and members are tasked at all times with upholding the organization's reputation and interests.

We are committed to evolving, this ambition cannot be under-estimated. Our goal is to take the patient voice of those affected by all liver diseases and play a credible key role in an international context, giving patients the power to improve patients' lives.

To that end, we look forward to supporting our members; to sharing personal stories to stakeholders and the wider general public; and to raising awareness regarding the barriers that they face including, the difficulties experienced with linkage to care within the health systems of their individual countries.

Finally, we recognize the great support from our medical professional, who always play a vital role in the elimination of liver diseases, while providing their knowledge and assistance to our cause.

MEMBER ORGANIZATIONS



Within our membership, we have a wide range of expertise and experience across a number of liver disease areas. For more information, please follow the link: liverpatientsinternational.org/our-members

Moreover, LPI are permanently open to new members, to forging new partnerships and to increasing the range of our work, our reach, and our knowledge in a manner that is engaging and meaningful to liver patients around the globe <https://liverpatientsinternational.org/our-members/>

2021 ACHIEVEMENTS AND PERFORMANCE



We, have in-spite of COVID restrictions this year successfully managed to make significant progress throughout 2021, accomplishing our 2021 targets and more. We are delighted to highlight some of our achievements below.

LIVE EVENTS/ WEBINARS

a. Facilitation 3 day Pipeline Advisory board

Creating an opportunity to inform our members of progress in treatments and diagnostics for liver diseases we facilitated a 3-day virtual Pipeline Advisory Board in December 2020. The progress of treatments and diagnostics for liver diseases is essential for liver advocates.

During the Pipeline Advisory Board sessions, industry representatives delivered presentations on new therapies, treatments and diagnostics these comprehensive presentations included issues regarding added value, side effects and details on how clinical trials are conducted for liver therapeutic areas.

b. Media training in Brussels

The delivery of this objective has been hampered by COVID restrictions however as we write this report we are preparing for an interactive two day program to be delivered in Brussels. Where an interactive multileveled program will be facilitated by ACUMEN PUBLIC AFFAIRS - ACUMENPA who will be covering media planning, building a campaign and the use of tools such as social media.

2021 ACHIEVEMENTS AND PERFORMANCE

ENSURING THAT THE LIVER PATIENTS VOICE IS CENTRAL

Ensuring the liver patient voice is central in all decision-making processes that impact on them and their well-being is essential and core to our beliefs. To that end we are committed to maintaining and developing our networks.

a. Development of LPI's Network

With collaboration being core to our mission, during 2021 we have expanded our networks, encouraging international Organizations and Associations to apply for LPI membership. This year we successfully launched our [Recruitment Plan](#) document which can be found on our website under [Become a member](#).

Established partnerships include:

- ACHIEVE Coalition (George Kalamitsis is co-chair)
- Correlation Network (partnership)
- ERN Rare Liver (Partnership)
- Global Liver Institute (GLI) (Partnership)
- EASL (Partnership – patient synergies) <https://easl.eu/patient-synergies/>
- HBCPPA – Hepatitis B & C Public Policy Association
- Civil Society Forum (CSF) HIV/AIDS, Hep and TB

2021 ACHIEVEMENTS AND PERFORMANCE

In addition this year we fostered and developed new key relationships with the following entities:

- Sayani- Association in Argentina
- SLAP- North Macedonia
- GAT- Portugal
- GLI
- ERN RARE-LIVER
- EURORDIS

Collaboration is a core principle within LPI and the addition of new members and partners gives us new opportunities for greater partnership working.

2021 ACHIEVEMENTS AND PERFORMANCE

b.Participation in patient expert groups

Representing the patient voice in expert groups is core to our work, during this year we have attended the following:

- Liver Cancers Council by GLI
- NASH Council by GLI
- Wilton Park virtual dialogue: Care Pathways for NALFD/NASH
- NASH patient expert group by Intercept
- EU PEARL Innovative Patient Centric Clinical Trial Platforms
- HCC Expert Series Webinar by ROCHE
- ILCN- International Liver Cancer network by ROCHE, ELPA and WHA.
- Webinar Bulgarian HepActive Association_Elimination of HBV/ HCV
- EASL's Love Your Liver Patient Art Competition
- 3rd EU HCV Policy Summit
- HBV Research 101 - Europe Focused Webinar by ICE-HBV
- EASL / ELPA – Beating liver cancer in Europe - The Empowerment of prevention and early detection

2021 ACHIEVEMENTS AND PERFORMANCE

RAISING AWARENESS OF VIRAL LIVER DISEASES, RARE LIVER DISEASES AND ISSUES THAT AFFECT LIVER PATIENTS SUCH AS COVID-19, NUTRITION AND ENVIRONMENTAL FACTORS THAT IMPACT ON THE OUTCOMES OF THOSE LIVING WITH LIVER DISEASES, THROUGH:

Sharing awareness material

At the onset of the COVID-19 pandemic it was apparent globally that information for vulnerable populations and the general public was varied and limited. The need for liver patient specific information was identified and in response a communications toolkit for COVID – 19 and liver patient organizations was developed. The purpose of the toolkit is to inform liver patient organizations on how they can support patients during this unique and challenging time. The document was developed by José Willemse and Martine Walmsley, patient advocates, in collaboration with RPP and endorsed by ERN Rare Liver and EASL, as part of the RPP Patient Grant scheme. It can be found on the LPI website and through the link below.

The toolkit has been built on three main pillars;

- Supporting patient associations to communicate accurate information about COVID-19 to patients,
- Providing advice and guidance on the use of social media and newsletters to make communication to patients easier
- Providing tips about how advocacy can be used to improve the situation and treatment of liver disease patients

**FIND THE
TOOLKIT HERE**

2021 ACHIEVEMENTS AND PERFORMANCE

Upscaling LPI's communications strategy:

A key focus of this year has been increasing our reach, essential within this has been the updating of our communications strategy with an emphasis on social media, details of which can be found below.

Website

Continuing to grow and expand our data base, we have also managed to further develop our [website](#), enriching it with more information on [liver diseases](#) section by adding information about [Hepatic Encephalopathy](#) sharing a [patient's story](#) in our news.

In addition we develop and produce a Newsletter every 3 months with and for our members- stakeholders and networks.

Social Media

Kicking off on January 2021 with 1.7k people reaching for our Facebook page, we have managed to reach 3,000 people with an average of 200 people clicking on our posts each month. We are continuing to grow by building our name within the liver community, regularly sharing posts with informative material and visuals, such as events from LPI directly or from our network.

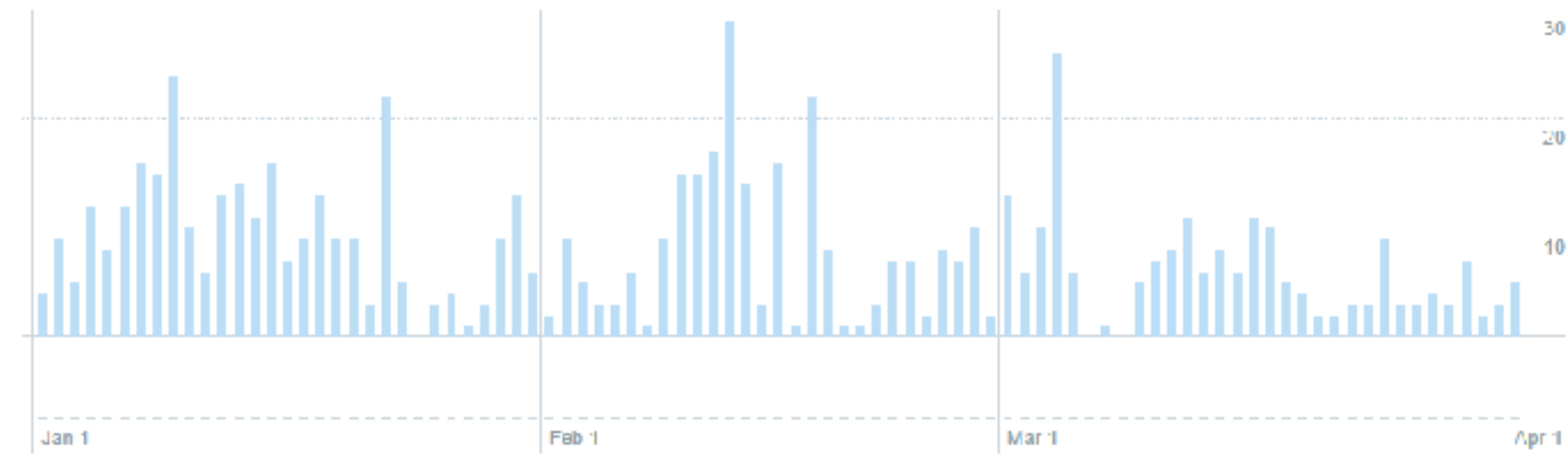
We are gaining popularity on Twitter, with our tweets reaching up to **10,000** impressions a month on average, meaning approximately 361 impressions per day. We are currently expanding our communications on LinkedIn.

2021 ACHIEVEMENTS AND PERFORMANCE - SOCIAL MEDIA OUTCOMES

TWITTER

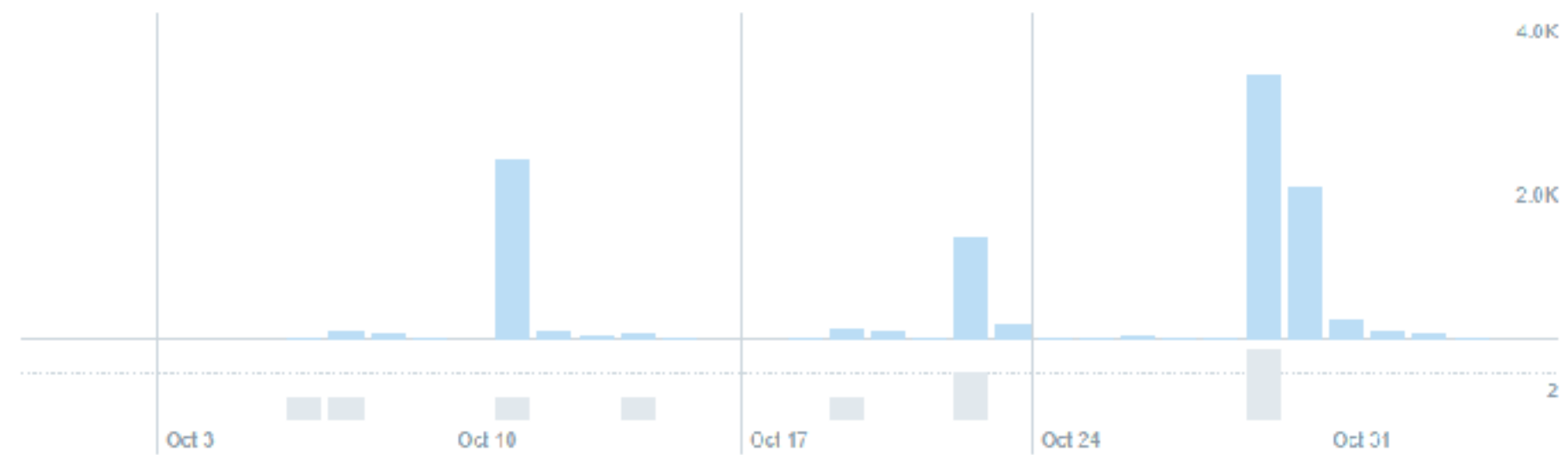
Quarter 1

Your Tweets earned **709 impressions** over this **91 day** period



Quarter 4

Your Tweets earned **10.1K impressions** over this **35 day** period



2021 ACHIEVEMENTS AND PERFORMANCE — SOCIAL MEDIA OUTCOMES



FACEBOOK

Total year to date

Results

Facebook Page Reach

2,937 ↓ 88.1%



June / Nash Day 2021

Results

Facebook Page Reach

158 ↑ 167.8%



July / World Hepatitis Day

Results

Facebook Page Reach

163 ↑ 2.5%



October / HCC Month

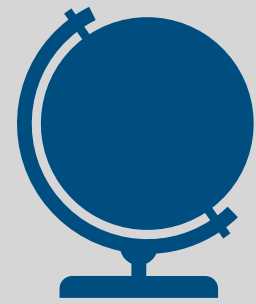
Results

Facebook Page Reach

529 ↑ 715.8%



INTERNATIONAL DAYS 2021



International NASH Day

Although the COVID-19 pandemic stalled the majority of our intended communication actions and awareness campaigns, LPI did successfully launch an awareness raising campaign on the NAFLD / NASH Day on June 10th, as part of the GLI Initiative.

As part of GLI's initiative, more than 80 partners from around the world engaged in activities, to promote prevention and motivate policy makers, health care professionals and the public, to address these diseases. Notably, GLI's initiative was endorsed by American Association for the Study of Liver Diseases (AASLD) and the European Association for the Study of Liver Diseases (EASL).

In addition, LPI, created a contemporary video focusing on NAFLD prevention as whilst introducing LPI to the community. The video was disseminated via LPI's social media channels and website, gaining notable attention from our international partners.

[PRESS HERE TO WATCH THE VIDEO](#)

International PBC Day

LPI members were involved in PBC Day, raising awareness of PBC through events, which included delivering information for patients on aspects of living with PBC.

INTERNATIONAL DAYS 2021

World Hepatitis Day

World Hepatitis Day is marked each year on the 28th July, to enhance awareness of viral hepatitis, an inflammation of the liver that causes a range of health problems, including liver cancer.

During the World Hepatitis Day 28th July 2021, through social media, we stressed the importance of governments remaining on track with viral hepatitis elimination by 2030, and the importance of the public joining the awareness raising efforts.

Viral hepatitis disproportionately affects marginalized people living in vulnerability. Hepatitis B (HBV) and Hepatitis C (HCV) are the most common cause of deaths, with 1.4 million lives lost each year. On World Hepatitis Day we underlined a number of important facts and WHO statistics.

Liver Cancer Awareness

During October as the #LiverCancerAwarenessMonth, we created social media content on liver cancer, which included highlighting that it is the 6th most common cancer globally close related to cirrhosis with hepatitis being the most prevailing risk factor for its development. Utilizing all our social media channels including our website we explained causes, risk factors and therapeutic treatments.

PFIC Awareness Day

Acknowledging the importance and burden of this rare disease, LPI congratulated the PFIC [community](#) on a new treatment approval via social media. LPI recognized a wonderful community on this important day for an under-recognized condition, standing with them and showing support online.

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THE YEAR AHEAD



As we move forward in the year ahead we will:

- Ensuring the liver patient voice is central in all decision-making processes that impact on them and their well-being.
- To raise awareness of viral liver diseases, rare liver diseases, and issues that affect liver patients such as Covid-19, nutrition and environmental factors that impact on the outcomes of those living with liver disease.
- Continue to increase our membership and widen the global reach of the liver patient voice
- Increase our social media presences including the introduction of you tube information videos

