



# Paris NASH Meeting

July 11 & 12, 2019  
Institut Pasteur  
5<sup>th</sup> edition

## Organized by

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With the partnership of





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# Patient perspectives on NASH and NAFLD

Marko Korenjak

President of European Liver Patients' Association





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# My disclosures

## **European Liver Patient' Association**

*AbbVie, BMS, Gilead, Genfit, Intercept, Janssen, MSD, Norgine, Novo Nordisk, Ipsen, Novartis, Roche diagnostics*

## **Slovenian Association Slovenia HEP**

*AbbVie, MSD, Medicopharmacia*

## **Consultancy, lectures, sponsored workshops**

*Lek, Novartis, AbbVie, MSD*





# Content of the presentation

- 1) *Introduction*
- 2) *Basic patient problems in NAFLD/NASH*
- 3) *Different view of the disease compared to chronic conditions*
- 4) *Patient view and the view of patient advocates*
- 5) *Next steps*





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# European Liver Patients' Association

- ✓ **Start 2004/2005**
- ✓ **31 ELPA members (30 + 1)**
- ✓ **25 countries**
- ✓ **50% management patient/family**

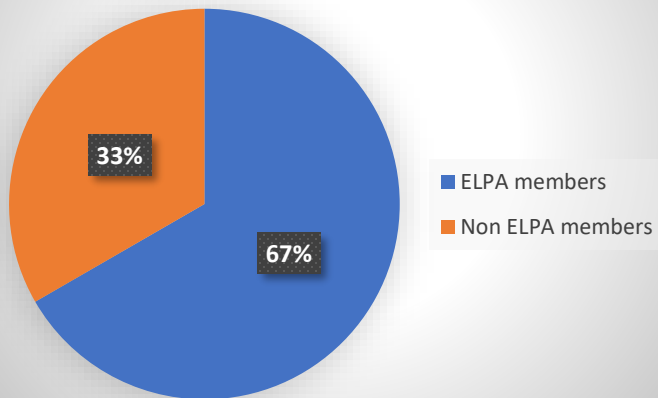




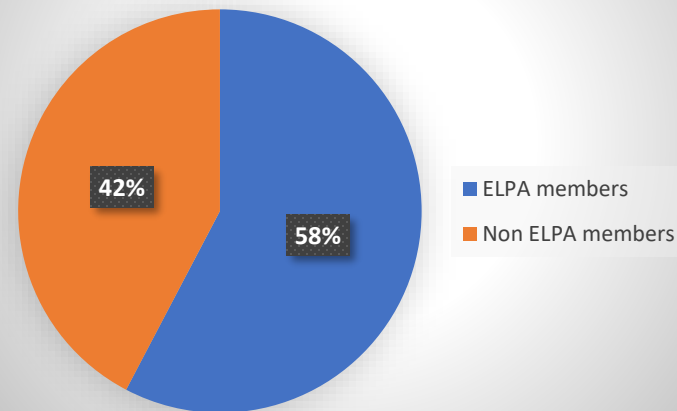
# European Liver Patients' Association



## European Union and ELPA members



## WHO European region and ELPA members





# European Liver Patients' Association

- ✓ One of 22 members of **Patient and Consumer Working Party** at European Medicine Agency
- ✓ Member of 35 **eligible patient organizations** at European Medicine Agency
- ✓ Member of **Civil Society Forum**
- ✓ **Lancet Commission**
- ✓ Chair of **ACHIEVE coalition**
- ✓ Member of **World Health Organization** Regional Collaborating Committee on Accelerated Response to Tuberculosis, HIV and Viral Hepatitis (RCC-THV)
- ✓ Member of Technical Committee of **Georgian Government** for elimination of hepatitis
- ✓ *Part of EASL Foundation NAFLD Policy Review, coreNASH project, Horizon 2020 ongoing projects (LIVERHOPE, MICROB-PREDICT, GALAXY), EIT Health research projects (2018 + 2019/2022), 6 Horizon2020 projects that are in the process of evaluation*
- ✓ ...





# Basic Patient Problems in NAFLD, NASH

- Who is my doctor?
  - **CONFUSION**
    - Should I consult hepatologists?  
Nutricionist? Gastroenterologist?
- What drugs I need to take? ➤ **LACK OF CHOICES**
- Did I do it to myself? ➤ **SELF-STIGMATIZATION**
- You did it to your self! ➤ **STIGMATIZATION**
- Where can I get more info? ➤ **LACK OF RELIABLE INFORMATIONS**
- Where can I turn for help? ➤ **LACK OF PATIENT ORGANIZATIONS**

**lifestyle changes**

**nutrition**







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# Our next steps

- ✓ Continue collaboration on patient involvement in research and other projects
- ✓ Collaboration on clear and easy to understand informations regarding NAFLD and NASH in Europe
- ✓ Collaboration on building strong patient communities
- ✓ Collaboration on joint actions in European Institutions



*January 2019 at European Commission*



*May 2017 in European Parliament*