Paris NASH Meeting

July 11 & 12, 2019
Institut Pasteur
5th edition

Organized by
Arun Sanyal
Virginia Commonwealth University School of Medicine,
Richmond, Virginia, USA

Lawrence Serfaty
Hôpital Hautepierre
Hôpitaux Universitaires de Strasbourg, France

Scientific committee
Quentin Anstee
Pierre Bedossa
Laurent Castera
Jean-François Dufour
Scott Friedman
Fabio Marra
Philippe Mathurin
Veronica Miller
Frank Tacke
Michael Trauner

With the partnership of

AFEF
Société francophone du diabète
THE FORUM For Collaborative Research
Patient perspectives on NASH and NAFLD

Marko Korenjak
President of European Liver Patients’ Association
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
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

- ELPA members: 33%
- Non ELPA members: 67%

WHO European region and ELPA members

- ELPA members: 42%
- Non ELPA members: 58%
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?
  • Should I consult hepatologists? Nutricionist? Gastroenterologist?

• What drugs I need to take?
• Did I do it to myself?
• You did it to your self!
• Where can I get more info?
• Where can I turn for help?

➢ CONFUSION
➢ LACK OF CHOICES
➢ SELF-STIGMATIZATION
➢ STIGMATIZATION
➢ LACK OF RELIABLE INFORMATIONS
➢ LACK OF PATIENT ORGANIZATIONS

lifestyle changes nutrition
Our next steps

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