

ELPA

European Liver Patients' Association

European Liver Patients' Association

17th June 2019

Content of presentation

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Source of the royalty free picture: <https://www.pexels.com/photo/photo-of-four-persons-uniting-hands-943630/>

Introduction of ELPA 2019

JUNE 2019

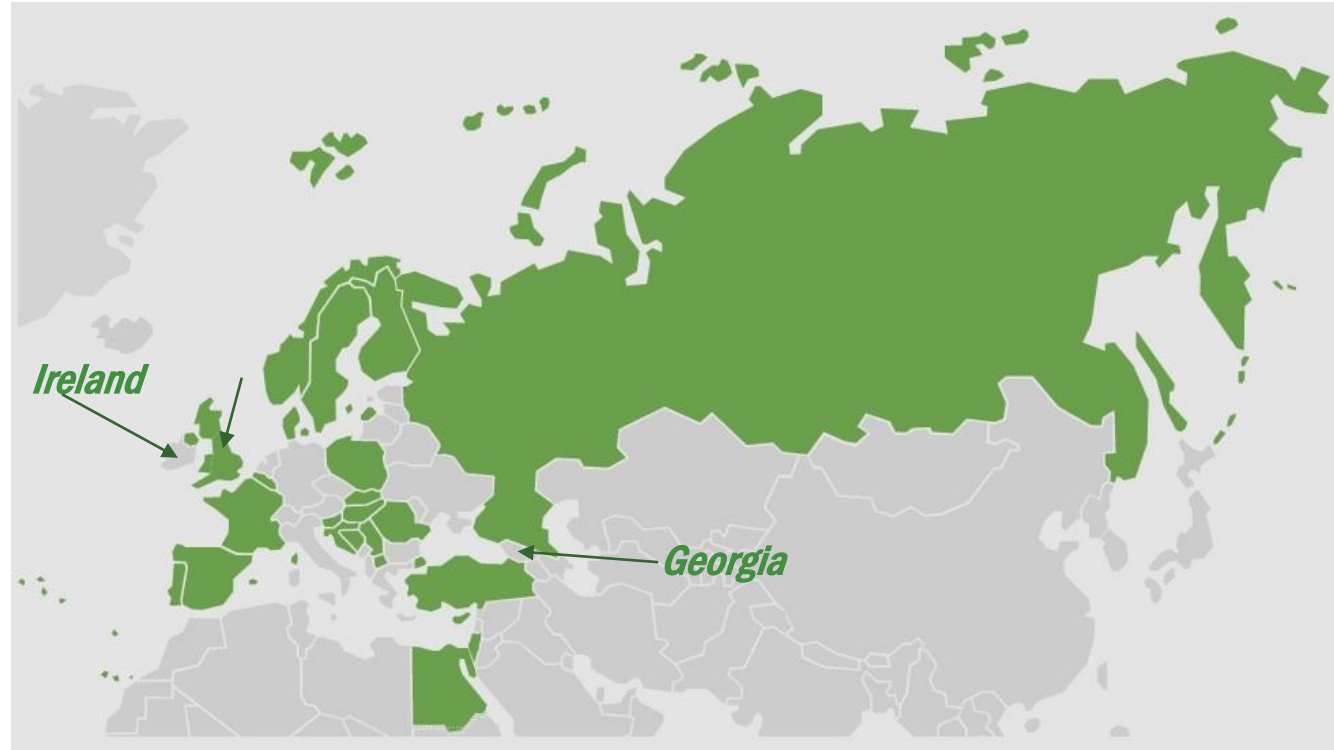
28 +3 members

25 countries

Start: 2004 / 2005

2019 = 14 years

*50% of management
must be patients*



2018 Changes

- During the 2018 (ELPA pre-election year) differences of opinion occurred
 - EGM was called

- For transparency reason office documents (copies) were moved to Ljubljana

2018 Changes



Members meant to lead healthy debate and determine way forward

2018 Changes



vivid discussion among patients' groups representatives showed once again that the liver patients' movement has come a long way, but that there is still some room for improvement / dissemination of false information externally



2018 Changes

- After a day long meeting where ELPA Board answered all members' questions elections were held
- ELPA members decided how they want to proceed: equity in full means of the word, not just declare but make implement it in real life with no double criteria, no privileged countries, equal opportunities...



2018 Changes

ELPA

European Liver
Patients' Association

After a day long meeting...



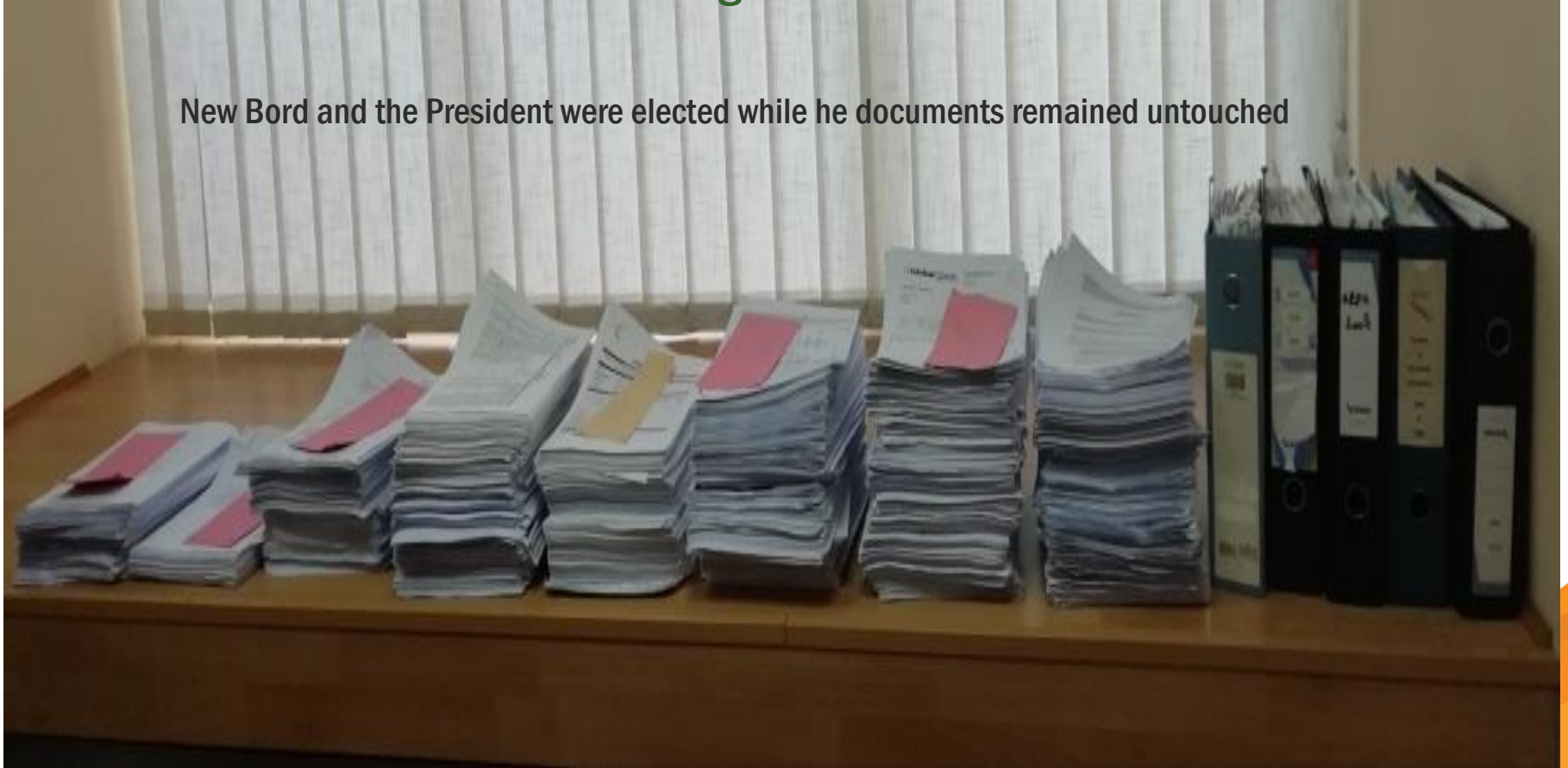
2018 Changes

- 12 hours after the democratic election 11 ELPA members have chosen to leave ELPA including the organizations represented by the 2 presidential candidates who were not elected/withdrew. One more joined them in a later stage
- ELPA member numbers continue to grow with the addition of new members from new countries

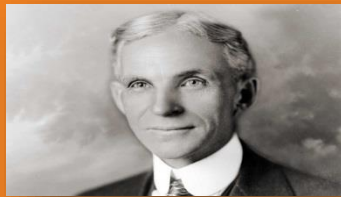


2018 Changes

New Bord and the President were elected while the documents remained untouched

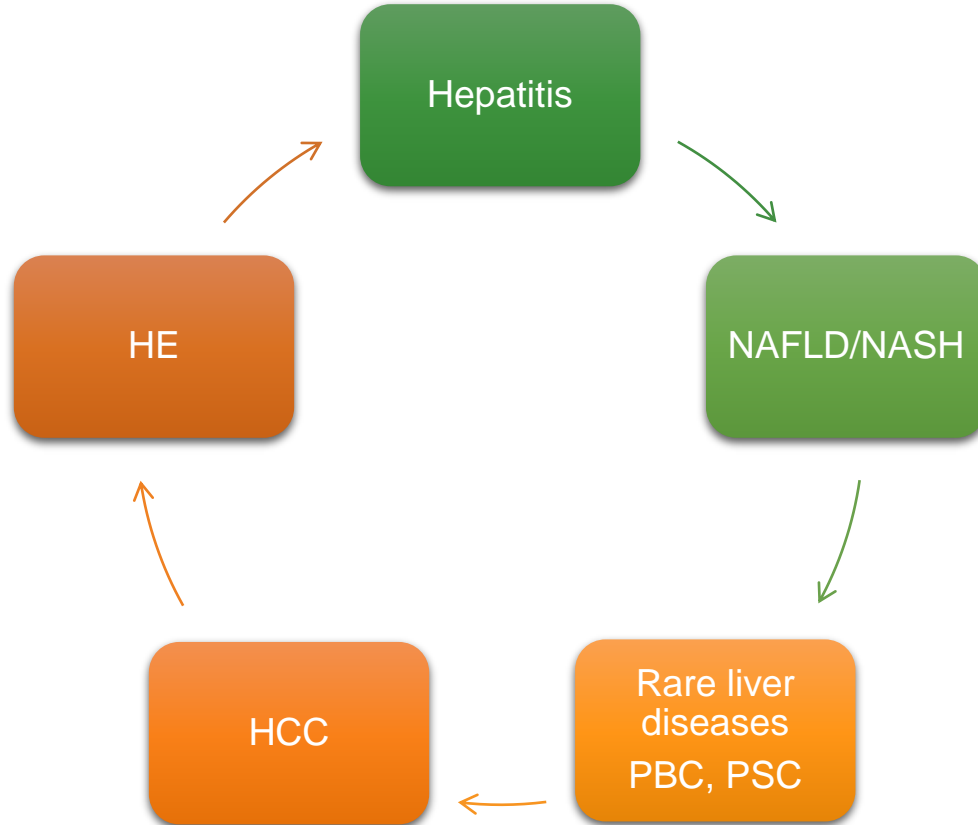


Coming together is a beginning;
keeping together is progress; working
together is success.



Henry Ford

Action fields of ELPA



Member empowerment

Policy/Advocacy work

Research projects

*“Do what you can,
with what you have,
where you are.”*

Theodore Roosevelt

ELPA and research projects 2019-2020

IN EVALUATION PROCESS (application on 16th April 2019)

- ✓ COMET-NAFLD
- ✓ DECISION
- ✓ H2020 LIVERSCREEN
- ✓ IP-cure-B
- ✓ ReLiveR
- ✓ FiSPlat EIT Health
- ✓ PROLIVER

FUNDED AND ONGOING

- ✓ LIVERHOPE
- ✓ MICROB-PREDICT
- ✓ GALAXY
- ✓ Hep-CORE

REJECTED

- ✓ CIRROTTRANS
- ✓ MARIE CURIE PhD
- ✓ RELIEF
- ✓ EJP RD JTC 2019

FINISHED

- ✓ EASL Foundation NAFLD Policy Review
- ✓ EIT LiverScreen

RE-APPLICATION

- ✓ MARIE CURIE PhD

**LiverScreen research project has received funding from the European Institute of Innovation and Technology (EIT). This body of the European Union receives support from the European Union's Horizon 2020 research and innovation programme.*



Key messages?

Elimination = everyone deserves to be treated.

„Easy to ignore groups“

Treat more than get infected.

National or European problem?



Our next steps ...

- ✓ Continue collaboration on patient view in decision making process
- ✓ Collaboration on clear and easy to understand informations regarding benefits for patients
- ✓ Collaboration on joint actions in European Institutions





Thank you for your time and attention!

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