# VISIÓN DEL PACIENTE HEPÁTICO EN EL ENTORNO EUROPEO

Diagnóstico y abordaje de las enfermedades hepáticas
Madrid, 24 de octubre de 2019

Dra. Teresa Casanovas, presidenta de ASSCAT y coordinadora del Comité Científico de ELPA (European Liver Patients' Association)

- Hemos vivido episodios excepcionales junto a personas extraordinarias.
- Lo explicamos hoy con una visión actual que supera barreras y que se ha ido consolidando en los últimos 50 años.

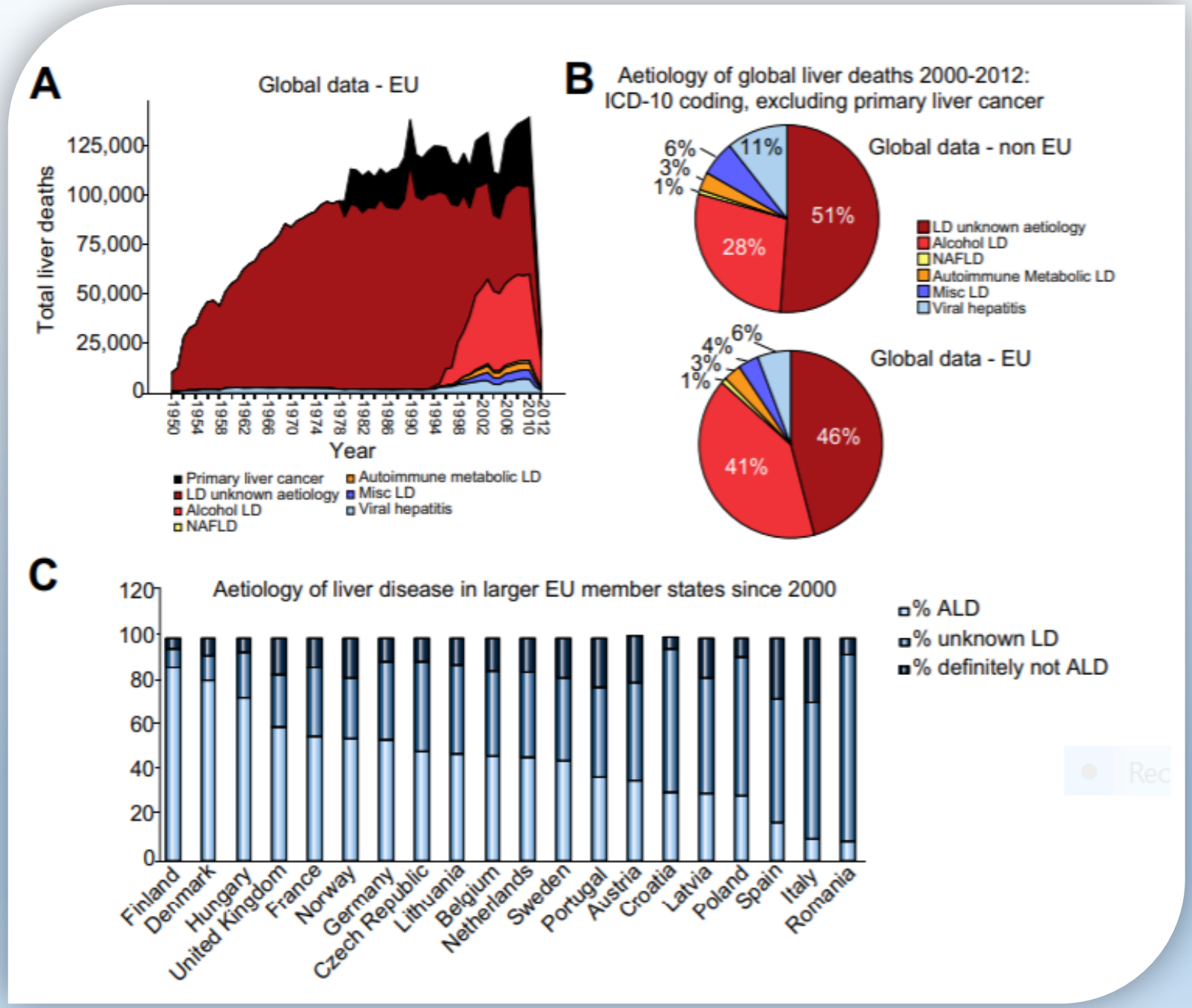
AVANCES DE LA HEPATOLOGÍA: MUCHA GENTE CAMINANDO EN LA MISMA DIRECCIÓN

# Índice de la presentación

- 1. Asociaciones de pacientes hepáticos, nos identifican nuestros objetivos: ayudar a las personas con enfermedades del hígado
- 2. ¿Qué hacemos? El trabajo del día a día, los proyectos y actividades, ASSCAT, ELPA, FNETH.
- 3. Visión de futuro

ELPA
ASSCAT
FNETH

# ¿Cuál es la experiencia de los pacientes en Europa?




N. Sheron. Alcohol and liver disease in Europe – Simple measures have the potential to prevent tens of thousands of premature deaths.
J Hepatol 2015

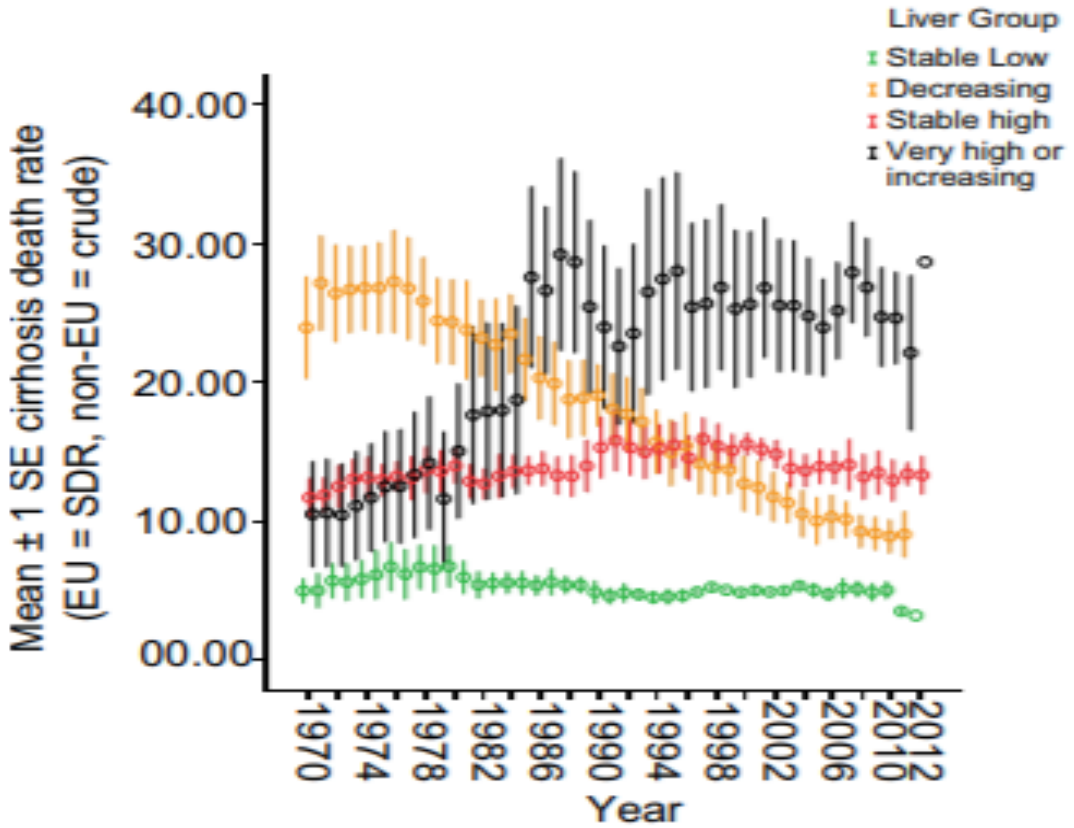
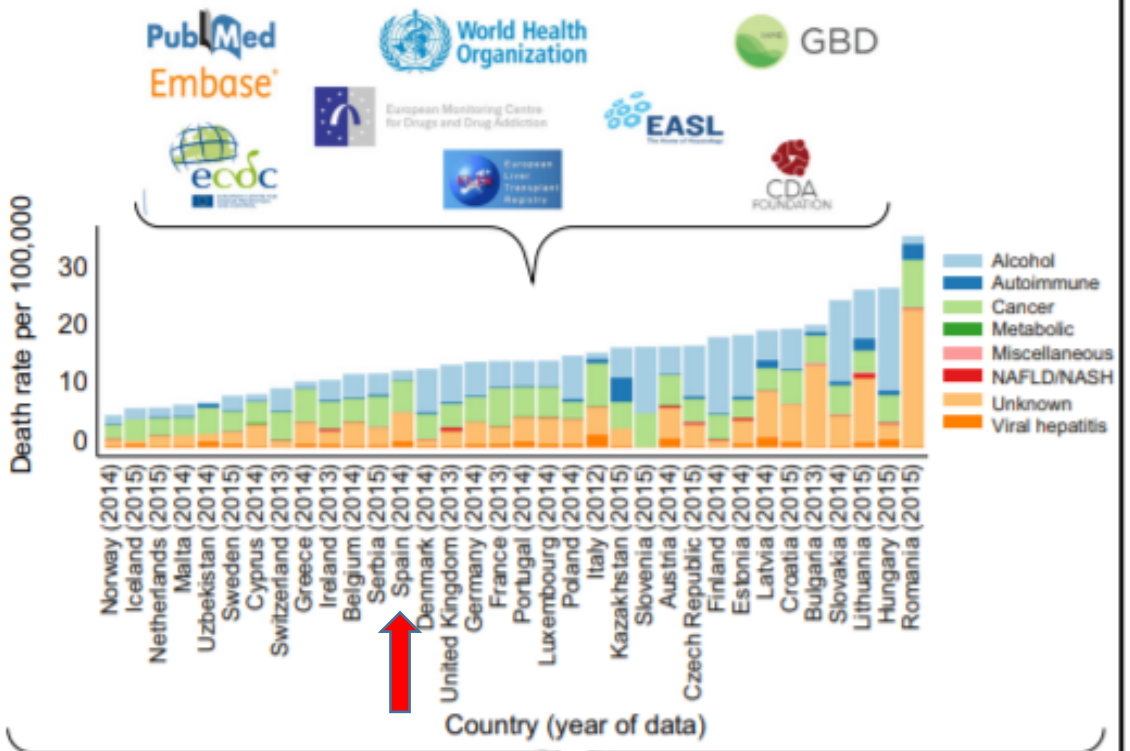



**Fig. 2. EU member states categorised according to mortality rate for chronic liver disease.** Stable low (green) – Cyprus, Ireland, Netherlands, Norway, Sweden. Decreasing (orange) – France, Greece, Italy, Luxembourg, Malta, Portugal, Spain and to some extent Austria. Stable high (red) – Belgium, Czech Republic, Denmark, Germany, Poland. Very high or increasing (black) – Bulgaria, Estonia, Finland, Hungary, Latvia, Lithuania, Romania, Slovakia, Slovenia, UK. Data from WHO HFA database [46], errors bars = mean (SE), plotted with SPSS, data om some of the newer EU members states was not available ll time periods.

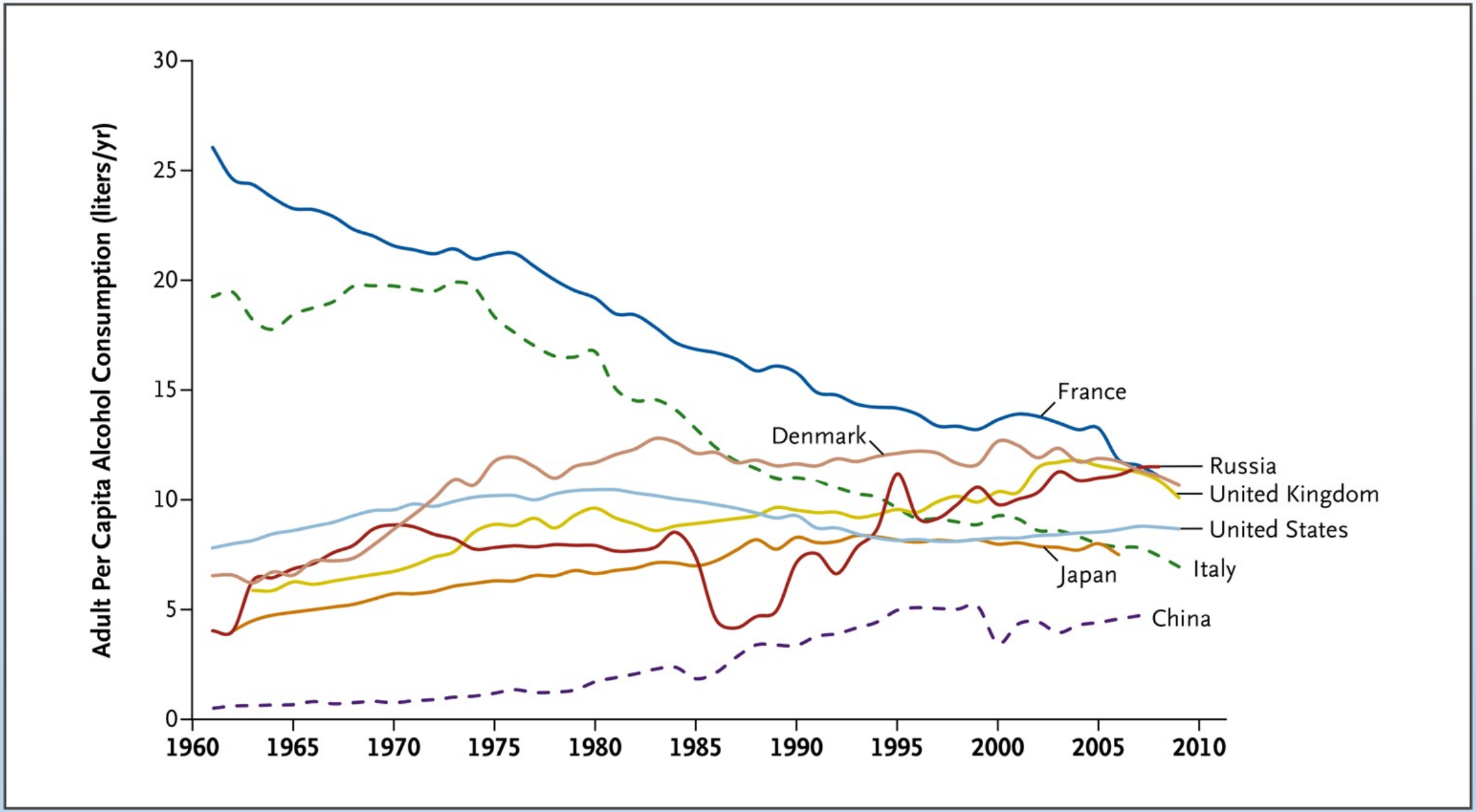
N. Sheron. Alcohol and liver disease in Europe – Simple measures have the potential to prevent tens of thousands of premature deaths. J Hepatol 2015




| Policy strategies | Alcohol | Obesity | Viral hepatitis |
|---|---|---|---|
| Fiscal and pricing | Taxation<br>Minimum unit pricing | Taxation<br>Subsidies | |
| Managing the environment | Marketing regulation<br>Licensing<br>Minimum age of purchase | Marketing regulation<br>Nutrition labelling<br>Product reformation | |
| Screening | Population level risk factor screening and referral to behavioural intervenions | Multi-component lifestyle interventions for weight management<br>• Behavioural<br>• Diet<br>• Physical acivity | Screening of at-risk groups |
| Behavioural interventions | | | Harm reduction services |
| Clinical | | | Immunisation (HBV)<br>Treatment as prevention |

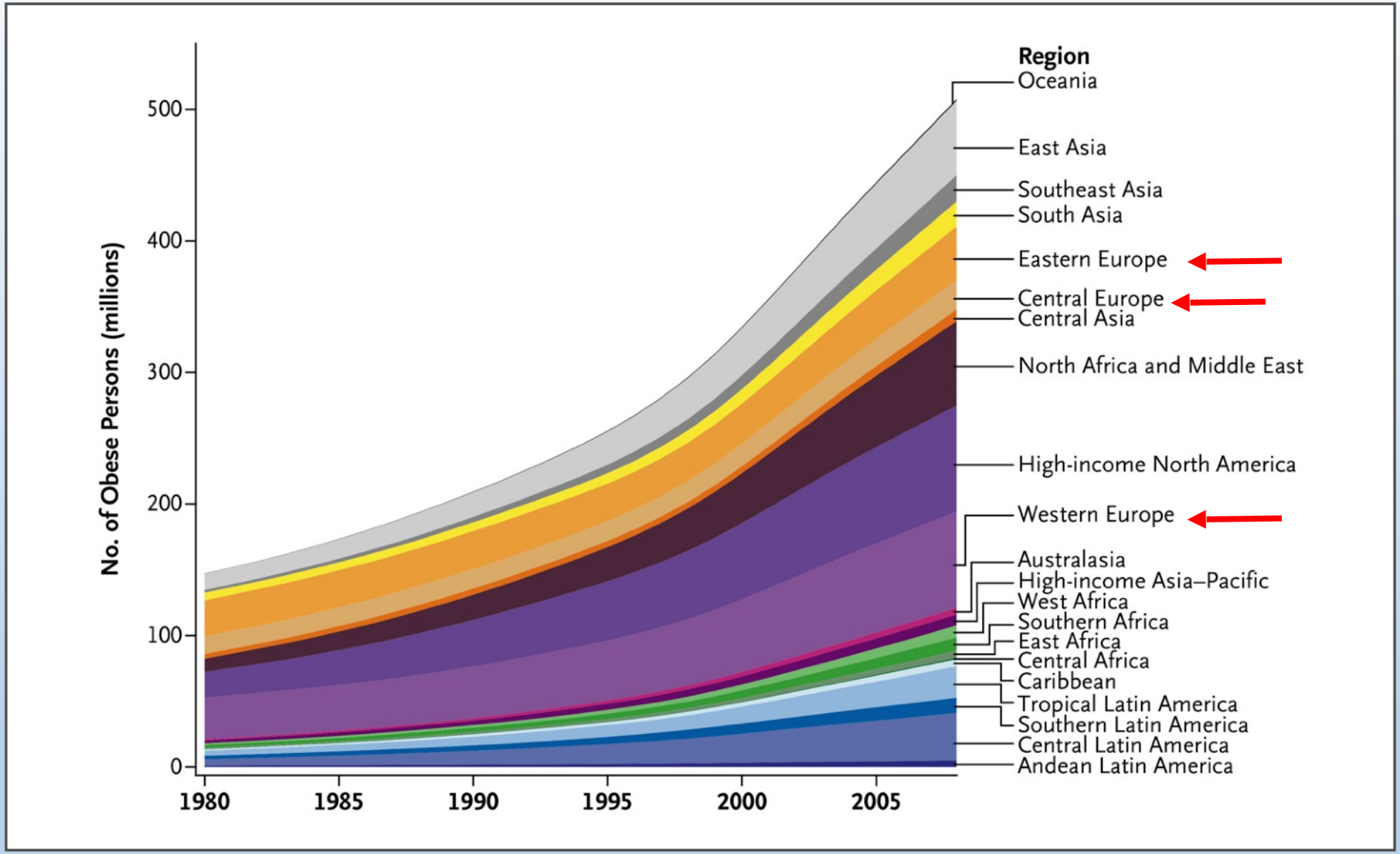
L. Pimpin et al.
Burden of liver disease in Europe: Epidemiology and analysis of risk factors to identify prevention policies. J Hepatology 2018

Poca información, estigma, falta de medidas de prevención, poblaciones marginadas, no tratamientos para todos…




Tendencia en el consumo de alcohol per cápita en algunos países. (*Data are from the WHO Global Information System on Alcohol and Health)* M Ezzati, E Riboli. *N Engl J Med 2013*

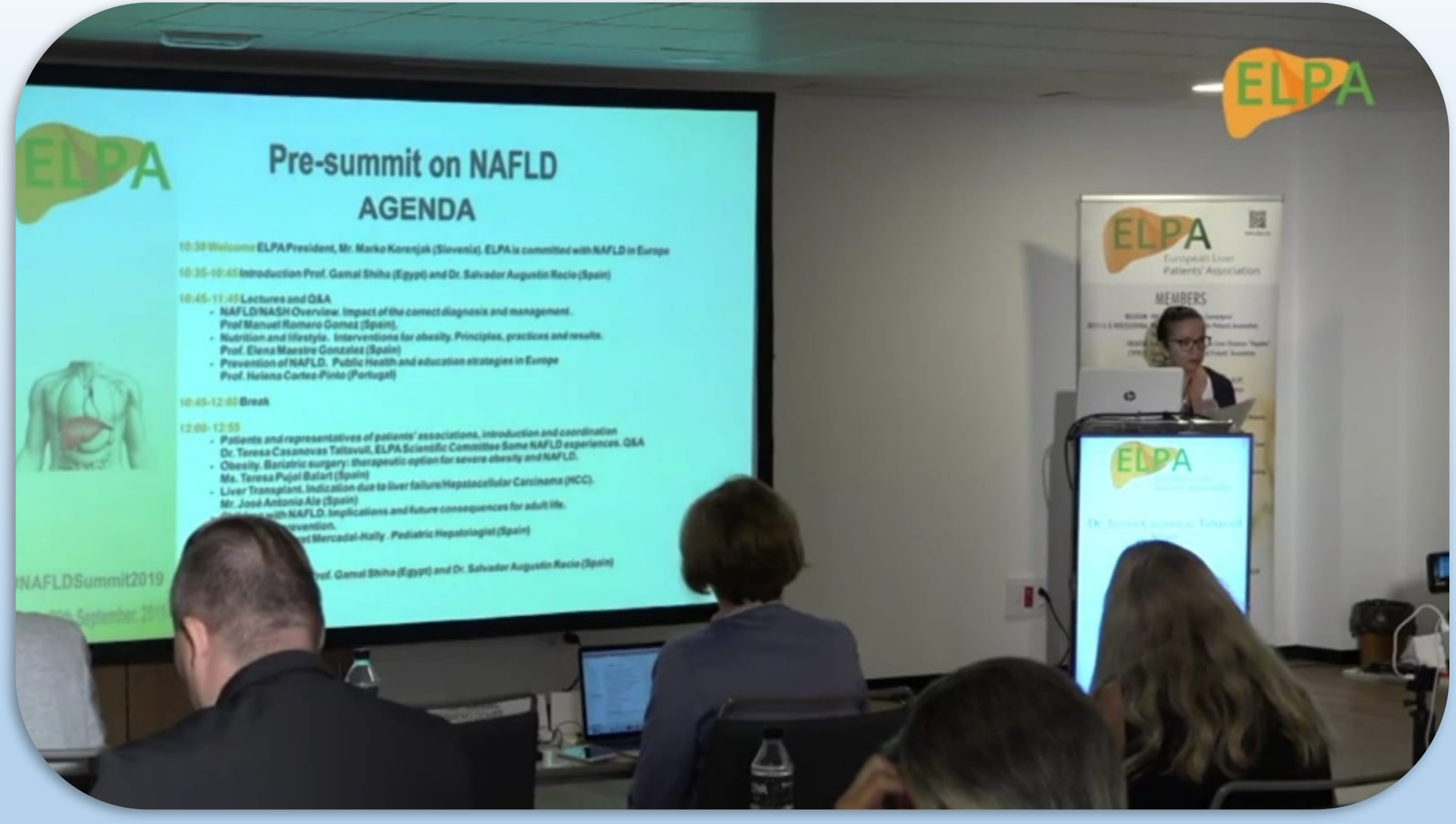
# A veces el camino es…




**Tendencias en el número de personas obesas, según la región. Definen obesidad como un IMC >30.**

M Ezzati, E Riboli. *N Engl J Med 2013*

Distintas velocidades, diferentes opciones, culturas diversas, múltiples sistemas sanitarios... El derecho a la salud es uno de los **Derechos Humanos** reconocidos.


ELPA
Pre-summit on NAFLD
AGENDA
10:30 Welcome ELPA President, Mr. Marko Korenjak (Slovenia). ELPA is committed with NAFLD in Europe
10:35-10:45 Introduction Prof. Gamal Shiha (Egypt) and Dr. Salvador Augustin Recio (Spain)
10:45-11:45 Lectures and Q&A
NAFLD/NASH Overview. Impact of the correct diagnosis and management.
Prof Manuel Romero Gomez (Spain).
Nutrition and lifestyle. Interventions for obesity. Principles, practices and results.
Prof. Elena Maestre Gonzalez (Spain)
Prevention of NAFLD. Public Health and education strategies in Europe
Prof. Helena Cortez-Pinto (Portugal)
11:45-12:00 Break
12:00- 12:55
Patients and representatives of patients' associations, introduction and coordination
Dr. Teresa Casanovas Taltavull, ELPA Scientific Committee Some NAFLD experiences. Q&A
Obesity. Bariatric surgery: therapeutic option for severe obesity and NAFLD.
Ma. Teresa Pujol Balart (Spain)
Liver Transplant. Indication due to liver failure/Hepatocellular Carcinoma (HCC).
Mr. José Antonio Ale (Spain)
NAFLD. Implications and future consequences for adult life.
Mercadal-Hally . Pediatric Hepatologist (Spain)
Prof. Gamal Shiha (Egypt) and Dr. Salvador Augustin Recio (Spain)
NAFLDSummit2019
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Europeans Liver Patients' Association
MEMBERS
ELPA

ELPA
European Liver
Patients' Association

#NAFLDSummit

# Pre-summit on NAFLD

## PATIENTS' EXPERIENCES & VIEWS on NAFLD

### Information for and from patients

Seville 26th September, 2019

ELPA

HOME DISCOVER MEMBERS MEDIA CORNER PROJECTS RESEARCH LIVER DISEASES NEWS

# ELPA Pre-Summit on NAFLD

26th September 2019 in Seville, Spain

ELPA

HOME DISCOVER MEMBERS MEDIA CORNER PROJECTS RESEARCH LIVER DISEASES NEWS

# ELPA Educational Days, 27-29 June 2019, Split

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

ELPA
European Liver Patients' Association

**ELPA FORMA PARTE DE LA PCWP**
(Patients' and Consumers' Working Party)
**DE LA EMA**

La Agencia Europea del Medicamento, **EMA**, es una agencia de la Unión Europea que se encarga de la evaluación de las solicitudes de autorización de comercialización de medicamentos en la Unión Europea y su supervisión.

Las circunstancias del camino pueden ser adversas

# The burden of liver disease in Europe

## The case of Hepatic Encephalopathy

ELPA
European Liver Patients' Association

### Key facts and figures

**The world is facing a veritable liver disease crisis.**[1] More than **844 million** people worldwide suffer from chronic liver disease (CLD).[2]

With a mortality rate of **two million deaths per year**, liver disease is comparable to other major public health epidemics, such as diabetes and pulmonary diseases. Europe has the largest burden of liver disease worldwide.[3] **500,000 EU citizens** are estimated to be living with **advanced chronic liver disease.**[4]

**Hepatic encephalopathy (HE)** is a serious complication of advanced chronic liver disease characterised by a loss of brain function, which occurs when the liver fails to remove sufficient toxins from the blood. As per the joint EASL and AASLD guidelines, **up to 80% of people with cirrhosis will develop minimal or covert symptoms of HE** during their clinical course, with up to **40% suffering from fully symptomatic overt HE.**[5] HE equals increases in hospitalisations, healthcare costs and mortality.[6] In Europe, HE is estimated to affect up to **200,000 people.**[7] However, the exact incidence of HE remains unknown.[9]

### Liver disease is comparable to other major public health epidemics

**Liver disease**[2]

**844 million** worldwide

**2 million** deaths

**Pulmonary diseases**[2]

**650 million** worldwide

**6.17 million** deaths

**Diabetes**[2]

**422 million** worldwide

**1.6 million** deaths

**HE is a serious complication of advanced chronic liver disease…**

**…and is estimated to affect up to 200,000 people in Europe**[7]

26 de febrero de 2019
PARLAMENTO EUROPEO

# Presentación del libro blanco de la encefalopatía hepática

ELPA
HOME
DISCOVER
MEMBERS
MEDIA CORNER
PROJECTS
RESEARCH
LIVER DISEASES
NEWS
The burden of liver desease in Europe: The case of Hepatic Encephalophaty - A policy roundtable at the European Parliament
Marko Korenjak
Hepatic Encephalopathy

Support, information, training
for patients and families
Projects:
1. Direct attention to patients
2. Web and social networks
3. Publications
4. World Hepatitis Day campaign
asscat

https://asscat-hepatitis.org/ca/
asscat
Compromís amb les hepatitis
Atenció, informació, sensibilització, visibilitat i suport comunitari
ASSOCIAT
PROPERS EVENTS

Si hay tratamientos eficaces y curativos, los pacientes queremos ir más rápido

Hepatitis C
is a curable disease.
You know this campaign and you joined. . For the first time in the world, over 400 volunteers came together for hepatitis C. This campaign has got a diffrent web page.

Miembros de ELPA de Suecia, España, Israel, Reino Unido y Croacia en el Congreso Internacional de la EASL en Viena, abril 2019

Miembros de ELPA tras la cena de despedida de las jornadas de formación en Liubliana (Eslovenia), noviembre 2018

ELSEVIER

Journal of Hepatology 51 (2009) 1068–1073

Journal of Hepatology

www.elsevier.com/locate/jhep

Special article

# Europe's hepatitis challenge: Defusing the "viral time bomb"☆

Nadine Y. Piorkowsky*

*European Liver Patients' Association ELPA, F. De Renesselaan 57, B - 3800 Sint-Truiden, Belgium*

- Los hepatólogos y los pacientes hepáticos se conocen tarde.
- Esto es frustrante para el primero y potencialmente fatal para el segundo, que a menudo se entera de su condición sólo después de décadas.
- Si se conociesen antes, muchas enfermedades hepáticas podrían controlarse o incluso curarse.

# Análisis DAFO para asociaciones de pacientes hepáticos en el momento presente

**Debilidades**

Puntos débiles internos que restan para lograr los objetivos.

**Amenazas**

Factores externos que dificultan el logro de metas.

**Oportunidades**

Puntos fuertes internos que ayudan a lograr los objetivos.

**Fortalezas**

Coyunturas externas que pueden potenciar el logro de las metas.

# Análisis DAFO para asociaciones de pacientes hepáticos en el momento presente

## Debilidades

-Falta de: experiencia profesionales, recursos, equipos y especialización

## Amenazas

-Temas novedosos
-Estigma
-Enfermedades asintomáticas

## Oportunidades

-Elevado nº de casos
-Nosotros estamos
-Organización

## Fortalezas

-Ya existimos
-Conocemos el sector
-Adaptación

# Objetivos

**TRABAJAR EN EQUIPO POR LOS PACIENTES HEPÁTICOS EN CATALUÑA, ESPAÑA, EUROPA y GLOBALMENTE**

**TERESA** **MARKO** **EVA** **MANU**

asscat Associació Catalana de Pacients Hepàtics

ELPA European Liver Patients' Association

FNETH

**¡Muchas gracias por su atención!**

Email: teresacasan@gmail.com