



EASL Patient Forum 2022: Barriers to Liver Disease Care: Exploring the Impact of Stigma and Discrimination

On 24 June 2022, and as part of the International Liver Congress™ (ILC) in London, the European Association for the Study of the Liver (EASL) held its annual Patient Forum on the topic: **barriers to liver disease care: exploring the impact of stigma and discrimination**. Patient advocates delivered inspiring and, sometimes, harrowing testimonies of their experience as people living with liver diseases. They exchanged their views on the different facets of stigma and its impact on patients.

To open the discussion, **Prof. Maria Buti, EASL Policy Councillor**, stated: *“I prefer referring to people living with liver diseases rather than referring to them as patients. This change is terminology is probably one of the first things we should think about changing.”* Prof. Buti stressed that, with the publication [of the EASL-Lancet Commission](#) on liver diseases, we realised that stigma is one of the most important barriers to fight liver diseases.

Ms Lone McColough from the European Liver Patients Association (ELPA) talked about the bias effect that stigmatisation can have on diagnosis of liver diseases. There is overwhelming evidence on what a person must go through – often accused of being alcoholic before the correct diagnosis is made. These false claims can cause long-term psychological damage. Ms Lone shared the story of a patient who waited up to 10 years for the right diagnosis to be made. He was falsely stigmatised as an alcoholic while his disease, haemochromatosis, was not related to alcohol consumption.

Building on this example, **Mr Robert Mitchell-Thain, from Liver Patient International (LPI) and PBC (primary biliary cholangitis) Foundation** stated that it is not only clinicians who have years of expertise but patients as well. He declared: *“let’s be patient experts and take ownership, not only of our experience but of our knowledge and expertise”*.

“The people who drink too much and have liver diseases are judged by the entire society” said **Ms José Willemse, volunteer at the European Reference Network for rare liver diseases and Executive Director of the Dutch Liver Patient Association**. These people are stigmatised as society insinuates that they are responsible for their disease. *“No one decides on a sunny day, let’s be an alcoholic! I believe that some people find that alcohol reduces their pain, and this is where the problem starts.”*

“Living with hepatitis B is one of the most traumatic experiences one could have in life.” said **Mr Danjuma Adda, President of the World Hepatitis Alliance**. When he got diagnosed, his first thoughts were on disclosure. Hepatitis and HIV infections are linked to sexual activities associated with moral decadence. *“If I disclose my status, I will be termed as morally bankrupt, then I have to hold back the information.”* Mr Adda said. He highlighted that the disease also impacts career as many employers would not pick a hepatitis or HIV positive person.



“I think the real change should start from the inside out, because when you, as a patient, realise it’s not your fault, then you can deliver the right messages to your community and that’s how changes start.” Stated **Ms Silvana Lesidrenska** from LPI.

Roberto Perez Gayo, who works at the **Correlation European Harm Reduction Network (C-EHRN)** focusing on access to care and quality of care for people who use drugs, highlighted that being infected with hepatitis C is associated with ideas of being an irresponsible person. The Network monitors actions on the ground to identify gaps that exist within healthcare systems, for instance, in some cases, treatments can only be prescribed by some specialists who are not in contact with people who use drugs.

“What really irritates me is victim blaming. We blame the victims while they are not to be blamed. If anyone is to be blamed, it is the industries that provide unhealthy products” stated **Prof. Frank Murray**, **EASL Policy and Public Health Member**. He concluded that *“to produce societal change and reduce the harm to patients, we really need to hear the patients’ voice”*.

Building on this, **Prof. Jeff Lazarus**, **EASL Policy and Public Health Member**, explained that when the World Hepatitis Alliance (WHA) was founded at the 2007 International Liver Congress in Barcelona, the patients didn’t attend the congress. There were no sessions that engaged patients, no sessions on public health topics. In the last 15 years, EASL made a major change in trying to include patient representatives and have sessions on public health related issues.

Reacting to a question on why there is so much stigma in healthcare settings, **Prof. Maria Buti** declared that *“some physicians are not aware of the stigma, for some physicians this is not an issue. Thus, involving patients in discussions with physicians is essential for them to realise the issues related to stigma.”* **Prof. Jeff Lazarus** added that there is strong evidence that because of stigma people are not coming forward for their diagnosis, they are not returning for their visits and medications. That’s the kind of language that resonates with clinicians that must be brought to their attention.

Closing the discussion, **Prof. Shira Zelber-Sagi**, **former EASL Policy and Public Health Member**, shifted the discussion to stigma and obesity. She stated that we need to shift the responsibility from patients with obesity to the environment. *“What are the chances of a child to not become obese if 50% of his daily calories comes from ultra-processed food? What are the chances of this child to not become obese if there is constant aggressive social media marketing of ultra-processed food and drinks? Nobody is doing anything to stop it. What do you do if you cannot afford fruits and vegetables but can afford ultra-processed food because it’s cheaper? We need to subsidize healthy food and we need to fight the aggressive marketing and change the environment. We need to get the industry to reformulate food.”* said Prof. Shira Zelber-Sagi.