

European Liver
Patients Association



ELPA Calls on Patients with Primary Liver Cancer (HCC) to Share their Experiences in First Global Survey

***Results will provide doctors and cancer researchers with
insights to improve liver cancer treatment now, and in the future***

ELPA has recently joined a special partnership with similar organisations across North America, Asia and Europe to ask hundreds of men and women with primary liver cancer (HCC) to share their experiences by responding to the first-ever international survey of people living with HCC.

The anonymous survey is available on-line and patients can access it on their personal computer at www.hcc-voices.com. Data privacy will be assured at all times. The survey will be available on the web until December 31, 2016. Patients who respond to the survey will also receive a personal copy of this report, which will allow them to compare their observations with those of the others who took part in the survey.

“We know that each patient’s personal fight against liver cancer is their first priority. However, each patient is also one among tens of thousands of people who are fighting a similar battle every day, in every country of the world. In fact, HCC today is the sixth most common cancer diagnosed each year, and the second leading cause of cancer deaths,” said Livia Alimena, ELPA Public Affairs Director.

“That’s why we hope many HCC patients will share the experiences of their cancer journey through this survey, to enable us to better understand and address the problems of living with HCC.”

In addition to ELPA, a number of other national liver cancer societies are asking patients to take part in the survey. These include the American Liver Foundation, Blue Faery – The Adrienne Wilson Liver Cancer Association, the British Liver Trust, the Canadian Liver Foundation, the Taiwan Liver Cancer Association and a number of liver cancer treatment units in major medical centres around the world. The survey was developed for these organisations by the research company, Strategic Sight, which will analyse the results in collaboration with the Medical Technology Research Group of the London School of Economics, with an unrestricted educational grant from Sirtex Medical Limited.

The results of the survey will be made available early in 2017, in the form of a report from the London School of Economics and the participating liver cancer groups. The survey findings will be made available to liver research organisations, scientific journals and the media.

The European Liver Patients Association (ELPA) emerged from a desire amongst European liver patient groups to share their experiences in fighting the burden of liver diseases and today has reached 35 members from 27 countries. ELPA's aim is to promote the interests of people with liver disease and in particular: to highlight the problems which patients with liver disease face; to promote awareness and prevention; to share experience of successful initiatives; to work with professional bodies such as the European Association for the Study of the Liver (EASL) and with the European Union (EU) to ensure that treatment and care for liver diseases are harmonized across Europe to the highest standards. For more information regarding ELPA initiatives for patients with liver diseases, visit www.elpa-info.org.

422-EUA-1016