

WebMD-UPMC Survey Finds Lack of Awareness About Liver Donation

Waiting List Deaths Fuel Need for Discussion about Living Donation

Washington, DC, June 14, 2019 – There are over 14,000 people on the national waiting list for a liver transplant, and around 20% will die before receiving a lifesaving transplant because of a lack of deceased donors. A new survey, *Understanding Attitudes and Perceptions About Liver Disease and Transplantation*, from WebMD and UPMC, reveals that lack of awareness, misperceptions and biases about liver disease and transplant – especially living donation – are contributing to this gap, keeping Americans from registering as organ donors and patients and physicians from discussing living donation as a first-line option.

The survey findings of over 4,600 consumers and 660 physicians come as living-donor liver transplant surgical techniques have vastly improved, drug therapies to prevent organ rejection are underway and effective strategies for matching patients with donors have been put in place. Despite these advances, deceased liver allocation issues remain unresolved, and cases of liver disease are on the rise, with rates of non-alcoholic fatty liver disease (NAFLD) expected to nearly double in the next decade.

Click here for more information: <http://www.webmd.com/livingdonor>

“Our survey results showed that people are willing to donate to save a life, particularly if they know the person, but, potential donors, patients and physicians may not know all available options, and others may have misperceptions about the transplant process,” said Abhi Humar, M.D., Division Chief, UPMC Transplant Services. “We need to increase awareness and knowledge.”

Though most respondents were aware of living donation and said they would be willing to donate to someone they knew, survey results clearly identified hurdles to increased donation. The percentage of those willing to donate sharply dropped to 39% for someone they didn’t know or for a patient needing a transplant due to substance abuse (36%). The primary reason respondents listed for why they were unwilling to donate were concerns about potential risks/danger (44%), uncertainty as to what’s involved (39%) and uncertainty about the costs involved (28%).

Additionally, just 48% of those surveyed said they’d be willing to ask a friend or family to donate if they needed a liver, and only 23% were willing to ask a non-friend/family member. Only 10% of those surveyed with liver disease said they learned about living donation from their physician, and approximately 43% of physicians reported a lack of knowledge regarding living-donor liver transplant.

Results of the survey indicate that a majority of people have a basic understanding of living donation and would consider this an option for their loved one, yet people are still dying on the waiting list due to a lack of education about living donation. WebMD and UPMC are committed to working together to provide better education about the benefits and risks of living donation among waiting list patients, potential donors and physicians to increase access to living-donor liver transplant and ultimately decrease waiting list mortality.

“No one should die waiting for a liver because a living-donor liver transplant is possible for virtually everyone on the waiting list, as well as those patients with a novel diagnosis preventing them from being placed on the list,” Humar added. “These results show that we must shift the paradigm so that all physicians and patients are familiar with living donation as a first-line option, rather than a last resort.”

The survey was conducted in February and March of 2019 via the WebMD and Medscape websites and queried people with and without liver disease, as well as physicians, about their own knowledge of liver transplant and living-donor liver transplant. Results were segmented by race, gender and ethnicity.

“There is much to be excited about in the field of organ transplant, yet misperceptions are hindering our ability to reap all the benefits,” said John Whyte, M.D., Chief Medical Officer, WebMD. “This lack of understanding showed by respondents contributes to the gap in donors and unnecessary deaths. We need to do a better job of communicating the realities of liver disease and liver donation, and change the misperceptions that surround the issue, particularly given the capacity for medical innovation to save lives through living donation.”

The findings were announced today at the Living-Donor Liver Transplant Summit at the National Press Club in Washington. The event featured speakers from the UPMC, WebMD, and leading advocacy and non-profit organizations, including Humar and Whyte, as well as David Fleming, CEO, Donate Life America; Brian Shepard, CEO, United Network for Organ Sharing; Tom Nealon, President and CEO, American Liver Foundation; and Swaytha Ganesh, M.D., Medical Director, UPMC Living Donor Program.

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