A recent study found that living donation increased 42% and the number of individuals who presented for donation evaluation increased 74% at centers in New York. The surge in live donation and donor evaluation occurred after additional education was provided to liver transplant candidates. Those candidates exposed to the peer-based intervention (education) reported significantly greater knowledge, greater likelihood to discuss donation and increased self-efficacy compared to those not exposed to the intervention. Details of the study are reported in the January 2010 issue of Liver Transplantation, a journal of the American Association for the Study of Liver Diseases, published by Wiley-Blackwell.

According to the United Network for Organ Sharing (UNOS) as of January 30, 2009 there were 100,539 candidates on the waiting list in the U.S., with over 15,000 individuals in need of a liver transplant. UNOS also reported the number of deceased donors is decreasing from 6,650 donors in 2006 to 6,494 donors in 2007—a concerning fact for liver transplant candidates. Past studies have shown that the median wait time for a liver was 296 and 306 days (2005 and 2006, respectively). In New York State in 2008, there were 133 deaths on the liver waitlist, an increase of 16% over 2007. The critical shortage of deceased liver donors, a lack of broader national sharing, increased wait times and deaths on the wait list, all incentivize transplant programs to look to alternative ways to expand the pool of livers available for transplant.

At the time of the study and based on UNOS data, New York had 1,947 individuals on the liver wait list which represents 12% of candidates nationally. In 2006-2007, random samples of waitlisted candidates at five transplant centers in New York were selected to complete (pre-intervention) surveys. A second sample of waitlisted candidates completed post-intervention surveys in 2008. These surveys included questions about: length of time on waiting list, education level, ethnicity, age, if they received educational materials (and helpfulness of materials), if they had discussed living liver donation with loved ones and if they had any plans to do so and where else they may have learned about liver transplantation.

“Past studies have show waitlisted candidates concerns over donor safety coupled with their general lack of knowledge about organ donation created a reluctance on the part of candidates to discuss living donor liver transplantation (LDLT) with family and friends,” said Samantha DeLair, Director, New York Center for Liver Transplantation and lead author of this study. “The intervention material we used included testimonials and self-report data from living donors to educate liver candidates about the impacts, both the positives and the challenges of living liver donation,” added Ms. DeLair.

In New York all living liver donors are periodically surveyed to assess the individuals’ health and quality of life post-donation. Educational material used in the study to educate liver candidates was derived from 44 survey respondents in 2004-2005. The content of the booklet and DVD focuses on: the surgery, recovery after donation, costs of donation, employment issues, and life after donation. The educational material used in this study, “In Their Own Words – The Experiences of Living Liver Donors,” may be accessed at www.nyclt.org/living_donor/.

Of the donors whose self-reports were used to create the educational material, 87% recommend seeking input of a former donor prior to donating. One anonymous donor gives this advice to individuals considering the option of LDLT, “Every decision is personal...get as much information as possible and speak to other donors.”

There were 437 waitlisted candidates at pre-test who completed surveys and 338 individuals at post-test. Participants had a median age of 55 years with 63% male and 56% of the total sample was White, non-Hispanic. Most surveyed were either newly listed (26%) or had been on the list for greater than 1 year (50%). For those participants exposed to the educational intervention, 91% reported having a “fair amount” or “a lot” of knowledge regarding LDLT compared to 70% of the unexposed group.

This study also tracked the number of friends and family members who presented to the five transplant centers for further information, discussion, and if appropriate, comprehensive evaluation for LDLT. Results indicate there was a 74% increase in LDLT evaluations from 2006 to 2008 at the intervention sites. After the educational intervention, there was a 42% increase in the number of individuals who completed an evaluation and donated a liver graft.

“Our data is compelling given the gains in waitlist candidates’ knowledge of LDLT and the increases in the number of individuals interested in using this transplantation procedure,” concluded Ms. DeLair. “It is important to follow live donors post-donation both for the donors themselves and to provide waitlist patients and their loved ones with as much information as possible as they consider live donation for themselves.”