

# Best Practices in Living Kidney Donation Consensus Conference

## Executive Summary

June 5-6 2014

A consensus conference was held June 5-6, 2014 in Rosemont Illinois to identify best practices and knowledge gaps pertaining to live donor kidney transplantation (LDKT) and living kidney donation (LKD). Sixty seven transplant professionals, patients, and other key stakeholders discussed processes for educating transplant candidates and potential living donors about living kidney donation; efficiencies in the living donor evaluation process; disparities in living donation; and financial and systemic barriers to living donation.

### Primary Objectives

To utilize a structured community-wide forum to identify and disseminate best practices for:

1. Educating transplant and donor candidates about LDKT and LKD.
2. Approaches, strategies, and tools to reduce disincentives for live donation across the patient, donor, and transplant spectrum.

### Background

The American Society of Transplantation's Live Donor Community of Practice (LDCOP) is a group of clinicians with expertise in living donation formed in 2012. Its mission is to advocate, support and advance the knowledge to improve the care of the live organ donor.

The LDCOP recognized the need to identify effective strategies to improve access to LDKT/LKD and improve LKD education and evaluation processes. A committee of LDCOP members identified five priority areas for best practices perceived to have high likelihood to immediately impact clinical practice when disseminated:

1. Transplant Candidate LDKT Educational Processes
2. Potential Living Donor Educational Processes
3. Strategies to Reduce Disparities
4. Strategies to Optimize Efficiencies in the LKD Evaluation
5. Strategies to Reduce Systemic Barriers to LKD

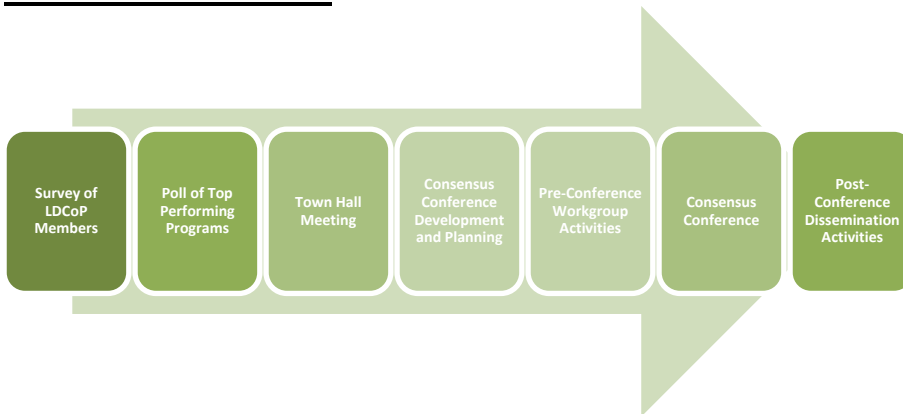
Committee members reviewed scientific literature and data from the Scientific Registry of Transplant Recipients (SRTR), polled 20 U.S. transplant programs with the highest LDKT volume/rate to identify center-level practices, surveyed AST members to identify potential best practices in core topic areas, and held a town hall meeting with 75 LDCOP members at the 2013 American Transplant Congress in Seattle, Washington. Three themes emerged: (1) the number of living donors has stopped increasing and may be declining, limiting LDKT access for many patients; (2) novel strategies to remove barriers to both LDKT and LKD are implemented at some, but not all, transplant programs; and (3) these strategies are not widely implemented nor have they been effectively disseminated, thus limiting their potential impact.

The LDCOP proposed a Consensus Conference on Best Practices in Live Kidney Donation, which was approved by the AST Board of Directors and subsequently co-sponsored by several organizations (Appendix 1). An Executive Planning Committee (EPC) was identified who worked together to identify 2 Leaders, 1 Facilitator, and 10-12 Members for each of 5 workgroups representing the core content areas identified

previously, with careful consideration for diversity by profession, program size, geography, and area of expertise. (Appendix 2)

## **Best Practices in Living Kidney Donation Consensus Conference**

### **Overview of the Process:**



In preparation for the conference, workgroups surveyed transplant professionals, reviewed scientific literature, reviewed clinical practices not reflected in empirical literature, examined international LKD policies, and held bi-weekly teleconferences to exchange information, deliberate, and debate. Each workgroup prepared a pre-conference document that: (a) summarized key issues discussed, (b) identified practices with evidence of effectiveness and promising practices for which more information was needed, (c) described potential problems in reaching consensus on best practices, and (d) proposed an agenda for research and public policy priorities. Documents were distributed to participants before the conference.

Sixty-seven physicians, live donor and transplant coordinators, allied health professionals, administrators, researchers, policy experts, patient organization representatives, government agency officials, and patients (donors and a recipient) attended the conference. Workgroup breakout and cross-talk sessions occurred during the first day, with specific workgroup recommendations presented in a final plenary session, allowing ample time for discussion.

### **Conference Recommendations:**

#### **Educational and Clinical Recommendations:**

- Develop a philosophical approach that LDKT is the best option for most transplant candidates and reflect this philosophy in educational processes
- LDKT education of patients with advanced stages of CKD should occur repeatedly throughout disease progression and transplantation processes (e.g., at evaluation, at waiting listing, at re-evaluation)
- Standardize LDKT content and processes across centers, to include comprehensive risk and benefit information about LKD, known fears or concerns about LKD, and stories about real-life LDKT and LKD experiences
- Provide patients and their caregivers with training about how to identify and approach potential living donors
- Provide more culturally-tailored LDKT education to racial/ethnic minority patients, with historically lower LDKT rates, and their support systems

- Educate community nephrologists and primary care physicians about LDKT so patients have access to transplant education earlier in the disease process
- Develop a process to ensure that transplant and dialysis team members attain competency in living donation risks, methods for communicating risks and benefits, and ways to provide guidance to transplant candidates on effective and ethical approaches to engaging potential donors
- Improve and expand the use of technology to better educate patients
- Implement an independent, national clearinghouse (e.g., website) for the general public and potential donors
- Increase awareness of the National Living Donor Assistance Center among providers, patients, and potential living donors
- Create a LKD Financial Toolkit, which includes a summary of LKD financial risks, estimation of costs, available financial resources for the donor, state tax laws pertaining to donation, and how the Medicare Cost Report can best be optimized by programs

### **Transplant Program Recommendations:**

- Develop a culture among members of the transplant center staff supporting the LKD program
- Hire dedicated living donor personnel, including a living donor coordinator and dedicated physician champion or director
- Ensure that systems and personnel are in place to respond immediately and thoroughly to living donor inquiries
- Carefully evaluate medically complex donors and inform donor candidates who are turned down because of these issues that they may have access to donation at programs with different eligibility
- Create an expedited process for transplant candidates with potential LKDs who are at lower risk/lower morbidity or who may be able to receive a transplant pre-emptively
- Participate in an active KPD program, or refer potential incompatible pairs to programs that do
- Collect and systematically review live donor metrics to measure efficiencies
- Create a quality improvement program to ensure ongoing evaluation and improvement of transplant candidate and living donor education about LDKT

### **Public Policy Recommendations:**

- Actively pursue strategies and policies that achieve the goal of financial neutrality for living donors, within the framework of federal law
- Improve and clarify CMS auditing of current transplant education practices within dialysis centers
- Expand OPTN policy pertaining to required educational elements for potential living donors, to include the higher risk of ESRD and pregnancy complications in kidney donors and additional psychosocial risks/benefits associated with donation and non-donation, as the evidence base evolves
- Modify the National Living Donor Assistance Center to eliminate financial means testing and to include some reimbursement for living donor lost wages

- Inform transplant programs of program-specific LKD metrics (i.e., LDKTs performed, LDKT rate, proportion of living donors by key sociodemographic characteristics in which disparities exist, and utilization of the NLDAC program), in comparison to regional and national data
- Develop and pass legislation that prohibits denial of coverage or increase in premiums of life or disability insurance for living donors
- Develop and pass legislation that ensures living donor surgery is considered a qualifying health condition under the Family Medical Leave Act
- Develop and disseminate uniform guidance to payers on coverage for living donor expenses
- Modify state tax laws to include a credit (vs. deduction) for living donation
- Create a living donor VISA program for non-residents

### **Recommended research priorities:**

- Examine the effectiveness of different strategies to optimize informed decision-making about LDKT and living donation
- Evaluate the impact of strategies to strengthen partnerships between community nephrologists, dialysis providers, and transplant programs on LDKT education, access, disparities, and rates
- Evaluate quality improvement initiatives to optimize the donor evaluation process and experience, reduce delays, and increase participation in kidney paired donation
- Examine strategies to reduce financial barriers to living donation, with particular attention to the impact on current disparities in LDKT

### **Dissemination:**

This Final Report summarizing the findings the consensus conference has been developed as a first step to inform all stakeholders regarding the outcome of the meeting and final recommendations for best practice. This will be distributed to all kidney transplant programs. A manuscript has been submitted for publication. It is our goal to continue dissemination of recommendations and collaborations regarding education, process improvement, research and policy changes to eliminate living donation and LDKT barriers.

Through the AST's LDCOP, there is an established mechanism to continue the work of the Consensus Conference with its partnering societies. Identified best practices will be disseminated to the medical community in the following proposed formats:

- Presentations at National Meetings
- A primary manuscript summarizing the meeting
- Secondary manuscripts from each workgroup to further discuss implementation of best practice
- Tool kits for programs, providers, patients and payors
  - Financial
  - Education regarding donor care
- Public education
- Collaborative public policy initiatives

## Appendix 1: Meeting Partners

The following societies, organizations, and companies provided financial support for the Consensus Conference:

- American Foundation for Donation and Transplantation
- American Kidney Fund
- American Society of Transplantation
- American Society of Nephrology
- American Society of Transplant Surgeons
- American Transplant Foundation
- Interlink
- NATCO
- National Kidney Foundation
- The Transplantation Society
- United Network for Organ Sharing

## Appendix 2: Meeting Participants

### Chairs

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### Leadership Group

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### Work Group Members

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