

# Advancing Living Donation: Helping Kidney Transplant Candidates Identify Living Donors

## Forum Report and Recommendations

January 23-24, 2020

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# Table of contents

Acknowledgements	4
Foreword	5
Executive Summary	6
Forum Purpose	6
Summary of Recommendations	6
Forum Recommendations	8
Context: The Chronic Kidney Disease (CKD) Patient's Continuum of Care	8
Training Health Providers	9
Assessing Patient Readiness	10
Timing of the LDKT Conversation	10
Format of Materials	11
Context: Stages of Readiness	11
Pre-Contemplation Stage	12
Contemplation Stage	13
Action Stage	13
System-level Recommendations	15
Commitments and Implementation	15
Donor and Recipient Insights	16
Meeting Reviews	17
Next Steps	18
Appendix I: Forum Overview	19
Welcome Address	19
Challenge Address	20

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Panel Discussion: Sharing Experience	20
Research Overview	21
Appendix II: Forum Participants	23
Steering Committee	23
Forum Participants	26
Appendix III: Acronyms and Definitions	28

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## Acknowledgements

This report provides an overview of the Advancing Living Donation: Helping Transplant Candidates Identify Living Donors Forum, held in January 2020 and summarizes participant recommendations in response to prescribed questions. The consensus recommendations were developed with the collaborative wisdom of a broad range of stakeholders and experts who provide care along the kidney transplant candidate's journey through chronic kidney disease clinics, various dialysis modalities and the transplant eligibility evaluation process; transplant recipients, transplant candidates and living donors were also included. The Steering Committee would like to collectively thank Canadian Blood Services, the forum facilitator Mike Tomlinson and the participants who helped in the execution of the workshop and the creation of these recommendations. They also wish to acknowledge Dale Orton, a living kidney donor, and Stephen Case, a kidney transplant recipient, for sharing their experiences as patients. This first-hand experience helped to ground the forum and situated the participants to the circumstances facing Canadians in need of a kidney transplant.

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## Foreword

Canadian Blood Services is responsible for operating and managing national interprovincial organ sharing registries and for leading the development of national initiatives and leading practices that will improve and increase organ and tissue donation and transplantation (OTDT) in Canada. Between 2008 and 2017, the living kidney donation (LKD) rate in Canada decreased by 12%. It is a strong possibility that this drop was influenced by potentially modifiable factors related to training, education, and support for the identification of living kidney donors.

In response, Canadian Blood Services' Living Donation Advisory Committee (LDAC) identified a priority need for increasing LKD by helping potential transplant candidates identify living kidney donors. In response, Canadian Blood Services hosted an Advancing Living Donation Forum focused on the identification of Living Kidney Donors on January 23 and 24, 2020, in Toronto, Ontario, Canada.

The Forum brought together 50+ clinical experts, kidney transplant recipients, transplant candidates and living kidney donors from across Canada to develop consensus recommendations. The perspectives of those who have gone through the living kidney donation process, who are actively looking for a living kidney donor, and who have received a kidney from a living donor were critical to the development of the recommendations in this report.

Participants agreed that a focus on improving and increasing patient and professional education was expected to increase identification of potential living kidney donors, and so raise the number of actual living kidney donor transplants in Canada. Research consistently demonstrates that a lack of knowledge and awareness about the benefits of living kidney donation among patients, health care providers and the public is an important and modifiable factor contributing to the current low rates of LKD. For example, one published needs assessment found that "...a majority [of frontline staff] also did not feel empowered to discuss [Living Donor Kidney Transplantation] LDKT with their patients..." and that "...approximately one-third of patients in advanced [Chronic Kidney Disease] CKD clinics were not adequately informed about [kidney transplantation] KT as a treatment option"<sup>1</sup>.

In planning the Forum, it was agreed that discussions would be designed with the understanding that the kidney transplant candidate was to be considered the centre of the education and awareness recommendations. The agenda was designed to follow the journey of the chronic kidney disease (CKD) patient along the continuum of their care, from chronic kidney disease clinics, to dialysis clinics (if applicable), to pre-transplant care. Accordingly, CKD clinic staff, dialysis providers, transplant nephrologists and kidney transplant candidates were key participants in the development of the recommendations.

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<sup>1</sup> Reference: Mucsi I, Novak M, Toews D, et al. Explore Transplant Ontario: Adapting the Explore Transplant Education Program to Facilitate Informed Decision Making About Kidney Transplantation. *Can. J. Kidney Health Dis.* 2018;5;1-9. [doi.org/10.1177/2054358118789369](https://doi.org/10.1177/2054358118789369)

# Executive Summary

## Forum Purpose

The purpose of the Forum was to develop pan-Canadian consensus on recommendations for improving the identification of potential living kidney donor candidates.

Objectives were to:

- examine and learn from existing research and programs;
- develop Canadian recommendations for improving the identification of potential living kidney donor candidates; and
- build commitment among Forum attendees to the implementation and evaluation of the recommendations adopted.

## Summary of Recommendations

The Forum recommendations follow the journey of the potential recipient from the chronic kidney disease (CKD) clinic, to being on dialysis if applicable, through to the transplant assessment process. These recommendations represent the “best case” scenario. Potential transplant candidates and living donation and transplant programs will incorporate them as each situation allows.

Forum consensus was achieved on the following statements:

1. Establishing a Program culture of “living donor kidney transplantation first” is an important first step. All team members need to be on board with LDKT being the best therapy and the first one that should be considered for patients who are eligible. Building a culture of discussing “LDKT first” whenever renal replacement therapy is needed, is key. Changing the culture includes increasing potential transplant candidates’ and health providers’ comfort with conversations that might be uncomfortable, at least in the beginning.
2. Educating patients with chronic kidney disease about living donor kidney transplantation is everyone’s work; all staff should be trained and equipped to discuss living donor kidney transplantation.
3. Living donor kidney transplant should be discussed early and often at every point of care of the potential recipient. A living donor kidney transplant is the best possible treatment option for transplant candidates. Every patient should know about living donor kidney transplantation as early as possible in their course of chronic kidney failure.
4. Deferred discussions can result in patients not having knowledge of the best treatment option for kidney failure and potentially missing a pre-emptive transplant opportunity (i.e., having a transplant before having to start dialysis), so living donor kidney transplantation should be discussed before exploring other kidney failure treatment options.

5. Strong communication among all health professionals generally, and between referring professionals and transplant professionals in particular, is essential.
6. Social workers are recognized as a feature of the success of Canadian programs with high living donor kidney transplantation rates. A trained social worker or health professional should meet with all patients in each setting to discuss living donor kidney transplantation.
7. Assessment for transplant, including assessment of patient readiness to discuss living donor kidney transplantation and to look for a living donor, should be integrated in professional training in LDKT.
8. There is no national standard with respect to patient and professional education on living donor kidney transplantation. As a result, there may be discrepancies in access to living donor kidney transplantation for patients in different provinces and attending different care clinics.
9. At each point in the patient pathway of care, potential recipients should have access to a standardized toolkit containing:
  - options for renal replacement therapy, including the benefits of pre-emptive transplant (i.e., having a transplant before having to start dialysis), and survival and quality-of-life benefits of a transplant vs. chronic dialysis therapy.
  - culturally sensitive/appropriate materials on how to start the conversation in finding a living kidney donor, coping with end-stage kidney disease (ESKD), and contacts for peer support.
  - risks and benefits of social media solicitation (i.e., looking for a living donor using social media posts).
  - self-assessment tools to understand personal readiness to discuss living donor kidney transplantation
  - detailed process map of the transplant assessment process, including logistics pertaining to living versus deceased donation, timelines and milestones, and contact information for living donation and transplant programs in Canada.
  - materials on preparation for, and recovery from, transplant surgery.

## Forum Recommendations

*This section describes the patient experience across the spectrum of End Stage Kidney Disease (ESKD) care, a key topic for Forum discussions. The collective wisdom and experience of the living kidney donors and recipients present, and of the health providers, is included here as context for the recommendations.*

### Context: The Chronic Kidney Disease (CKD) Patient's Continuum of Care

1. The **CKD clinic** provides care for those with established chronic kidney disease progressing at various rates. These clinics are often referred to as Multi-Care Kidney Clinics (MCKC) and involve a group of multidisciplinary care providers. For many, this may be their first exposure to discussing renal replacement therapy (RRT), particularly transplantation. Many may still be in the pre-contemplative phase of transplantation in these clinics, with no intention to change behavior in the foreseeable future as they are unaware or under-aware of their problem. For many, this is also an opportunity for clinicians to introduce the idea of pre-emptive living donor kidney transplantation. These clinics allow for the early introduction of living donor kidney transplantation (particularly pre-emptive LDKT) as the treatment of choice for ESKD.
2. **Dialysis clinics** (hemodialysis or peritoneal dialysis [PD] or home hemodialysis) are attended by individuals with established ESKD where hospital-based hemodialysis, peritoneal dialysis, or home hemodialysis has been selected as the RRT of choice. There may be varying degrees of exposure to the idea of transplantation in the dialysis clinic based on how the individual progressed to ESKD and where/by whom they were cared for and the time frame in which they progressed. The hemodialysis clinic is a setting that allows for ongoing discussion of transplantation, where applicable, or introduction to the idea of transplantation as a possibility. Some individuals on dialysis may be very unwell and unable to hear and process new information so support systems are particularly important for these individuals.
3. In the **Pre-Transplant Clinic**, or the transplant assessment clinic, individuals cared for in either a **CKD clinic** or a dialysis clinic are seeking to understand if they are eligible for transplantation. This is an important opportunity to discuss/repeat the importance of living donor kidney transplantation and encourage finding a living donor (and the advantages of this) if this information has not already been broached in other care settings.

Individuals in all the care settings listed above may be at various stages of readiness to explore transplant. Therefore, considerations based on stage of readiness are included in this report.



## Training Health Providers

- a) Forum participants recommend across all three settings of patient care (CKD clinic, dialysis units/clinics, transplant centres) that:
1. A dedicated LDKT champion on each care team lead transplant discussions.
  2. There be standardized training for all members of the healthcare team on:
    - discussing transplantation, both living and deceased donor transplantation, as a treatment for kidney failure.
    - assessing patient readiness for discussing transplantation and LDKT. (Consider a standardized 'eligibility/readiness for transplant' checklist.)
    - benefits and complications of living donation and transplantation.
    - potential emotional burdens, e.g., recipient guilt.
    - how to have difficult/uncomfortable conversations to explore barriers and help transplant candidates move forward.
    - local transplant process, logistics and available options; knowledge of where to find information in multiple formats; and knowledge of common misconceptions.
    - perceptions of risk relating to donor harm.
  3. A plan to ensure that these discussions are occurring with each patient should be developed. A position statement in support of a "LDKT first" transplant culture is strongly encouraged
  4. Conversations regarding LDKT happen early and often, with key messages delivered at opportune times (as determined by the patient's readiness).
  5. Health care providers have access to regular and ongoing training. This is an important consideration given the frequent staff turnover in health care settings.
  6. LDKT education should be a core competency for all staff working in CKD, dialysis and transplant environments.
- b) Additionally, for the CKD Clinics, forum participants recommend that:
7. LDKT be presented as the preferred treatment for those who may be eligible, before discussing other options.
  8. Nephrologists and other members of the care team in CKD clinics raise LDKT as a consideration at the earliest opportunity with patients.
  9. A referral to a transplant centre for assessment of transplant eligibility be part of the standard of care, if deemed appropriate by the referring Nephrologist.

A health care professional with frequent contact with patients on dialysis (e.g., the patient's primary nurse, in some units) takes on a primary role in discussing LDKT, with additional dedicated staff available to provide advanced education.

### *Considerations*

- Key messages: Discussions regarding LDKT should be done early, with consistency and at multiple points. All team members should support a culture of "LDKT first."
- In some unique circumstances, these discussions may be best raised by nephrologists (e.g., unique patient factors make transplant eligibility unclear).
- Transplant ambassadors are important but may not be available in all programs. Where possible, a dedicated LDKT ambassador is highly valuable. Comprehensive training on LDKT for staff involved in the circle of care of patients is another option.

## **Assessing Patient Readiness**

- c) Forum participants recommend across all three settings of patient care that:
1. Nurses, social workers and nephrologists should be key participants in ensuring LDKT has been considered for the patient.
  2. Nurses, social workers and nephrologists should be educated and prepared to assess patient readiness to consider living donor kidney transplantation.
  3. Patients that are identified as "not ready to discuss LDKT" should be offered the opportunity for referral to peer support (if available) for assistance, if they wish.
  4. Programs should encourage a family member or friend to attend education sessions with the patient, when possible, to engage in the process of discussing LDKT with others.
  5. Standardized patient readiness assessment tools should be available and included in the toolkit for healthcare providers.
  6. Transplant ambassador/peer support programs should be established and used to support patient readiness.
  7. Transplant education should be documented in a highly visible and easily accessible area of the patient chart to support the team in their collaborated approach in assessing patient readiness to discuss living kidney donor transplantation.

## **Timing of the LDKT Conversation**

- d) Forum participants recommend across all three settings of patient care:
1. LDKT should be discussed early and often, particularly if the patient is deemed eligible for a transplant.

2. Each program should include LDKT education for all eligible patients in their patient care map.
3. A transplant education assessment should be added to patient rounds; topics include transplant evaluation, LDKT, and deceased donor kidney transplant.
4. Transplant candidates and their potential donors should be connected with peer support as soon as possible in the process, if desired.

### *Considerations*

- Discussing LDKT can be a sensitive subject for some patients and may require an appointment outside of the typical care setting.

## **Format of Materials**

- e) Forum participants recommend across all three settings of patient care that:
- Limited, high-level information should be presented first, with more detailed LDKT information provided subsequently, particularly if eligibility for transplant has been established.
  - Materials should reflect Canadian context, be culturally sensitive, and available in both official languages as well as other common languages in Canada, and cover the benefits and risks of LDKT as compared to other therapies.
  - Materials should be tailored to the needs of the patient for their stage of readiness at the time and available in multiple formats including print, video, online, etc. as a “toolkit.”
  - Materials should include a recipient checklist for transplant readiness.

### *Considerations*

- Separating medical visits from educational sessions may be beneficial for some individuals in order to focus on LDKT information.

## **Context: Stages of Readiness**

Forum participants discussed helping a patient to find a living donor in the context of the stages of readiness to be able to discuss LDKT after a diagnosis of ESKD. For the purposes of this report we have selected three main states of readiness for recommendations: Pre-contemplation, contemplation and action.

In the **pre-contemplation stage**, one can expect an individual to be unaware, unable or unwilling to discuss LDKT. In this stage, it is helpful to establish a rapport with the patient, introduce the idea of LDKT, acknowledge the patient’s thoughts, feelings, fears and concerns, and provide awareness of the possibility of LDKT.

In the **contemplation stage**, the patient may be ambivalent or uncertain about their interest and feelings about LDKT. The person is interested in discussing LDKT and assessing potential

barriers to LDKT (discomfort with asking a potential donor, time and expense for the donor, etc.). At this stage, patients may be more receptive to receiving information and begin to ask questions about the process and what it might mean for them and the potential donor. Clarifying the patient's needs by asking questions such as, "What's most important to you and why?" is often important during the contemplation stage.

When the patient is ready to act, they demonstrate steps toward behavior change (preparation) such as asking for tools to help with donor identification and approaching family and friends.

## Pre-Contemplation Stage

For patients assessed as being in a pre-contemplation<sup>2</sup> stage of readiness, Forum participants recommend the following messages/approaches across all settings:

1. Understand patient goals about what is important to them for their health care and quality-of-life, including being able to be free of dialysis. Raise awareness about transplantation while avoiding 'trying to convince' patients.
2. Encourage the utilization of peer support and peer support groups. Peer support programs are currently being tested as part of the "Enhance Access to Kidney Transplantation and Living Kidney Donation (EnAKT)"<sup>3</sup> study in which transplant ambassadors speak about transplantation and living donation in renal programs across the province of Ontario.
3. If the patient is willing, encourage presence of family members or friends as part of the conversation. They are often important support persons and may also be able to act as a "champion" for an individual with CKD/ESKD.
4. Offer patients an opportunity to discuss concerns and fears at a time that works for them. Give patients an open-ended offer to begin the conversation again once they are ready.

## Considerations

- If the patient is open to discussion, address potential myths and misconceptions about transplantation and living donation that may exist. The goal at this stage is awareness, if they are ready to hear it.
- Broad dissemination of information about LDKT (beyond the patients and their providers) to the public is important in achieving widespread knowledge and acceptance of LDKT.

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<sup>2</sup>Pre-contemplation, Contemplation, and Action are a simplified version of a commonly used patient readiness model first presented in: Prochaska, J.O. and DiClemente, C.C. (1983) Stages and processes of self-change of smoking, toward an integrative model of change. *Journal of Consulting and Clinical Psychology*, 51, 390-395.

<sup>3</sup> Enhance Access to Kidney Transplantation and Living Kidney Donation - [ClinicalTrials.gov](https://clinicaltrials.gov)

## Contemplation Stage

For patients assessed as being ready to contemplate LDKT, Forum participants recommend the following key messages or approaches across all settings:

1. Discuss the risks and benefits of transplantation versus chronic dialysis therapy. For most subgroups of the ESKD population, transplantation results in better patient survival and quality-of-life as compared to dialysis. LDKT is preferred over deceased donor kidney transplantation as it results in superior patient and graft survival.
2. Discuss the option of Kidney Paired Donation. In cases where a donor-transplant candidate pair are incompatible due to ABO, HLA, size, age, etc., the Kidney Paired Donation Program could be considered as an option to facilitate a LDKT for the candidate.
3. Discuss strategies for finding a potential living kidney donor. Examples include reaching out to family or friends who may become a potential support network for the potential transplant candidate or a champion for helping them find a living donor; sharing information about living kidney donation with those that are closest to the potential candidate; and providing information about tools that are available for helping with finding a living kidney donor (such as social media apps designed for this purpose).

### *Considerations*

- More detailed information or statistics pertaining to transplantation, logistics and process may be requested and may require that the patient be directed to other resources (i.e., educational sessions at a transplant program, web resources, etc.)
- Continue to encourage peer support during the contemplation stage.

## Action Stage

For patients assessed as in the stage of readiness to act, Forum participants recommend the following action across all settings:

- Provide information and access to resources such as: contact information for support resources, including in-person educational sessions; educational materials for potential donors; template letters and social media messaging; advice regarding the benefits and pitfalls of social media solicitation; and strategies for approaching potential donors.
- Referral to transplant clinic for education and assessment, when appropriate.

### *Considerations*

- Some individuals referred for transplantation will be assessed as ineligible for transplantation. Furthermore, there are nuances of differences in the triage process of individual programs. CKD clinicians and dialysis clinicians should familiarize

themselves with their local transplant centre's transplant evaluation and donor evaluation practices before discussing referral with patients.

- Recipient and donor assessment teams are generally kept separate. Donor health information must always remain confidential and cannot be discussed directly with the potential recipient as it is private health information of the donor and must be protected as such.

## System-level Recommendations

*While system-level improvements were not the focus of this forum, Forum participants did acknowledge the importance of system performance.*

Forum participants recommend the following system-level considerations for all renal and transplant programs:

- Effective and regular communication is essential:
  - Ongoing communication between living donor and recipient teams, as well as between transplant programs and referral centres was felt to be an important aspect of system performance warranting ongoing attention.
  - Participants highlighted the importance of ongoing communication of patients' transplant eligibility status to the referring program.
  - Participants discussed the importance of continuing to build strong links between CKD/dialysis clinics and transplant programs to provide support and accurate and consistent messaging.
- Ensure an efficient and patient-centred evaluation process for potential transplant recipients and living kidney donors.
- Timely referral of potential transplant recipients is important. Consensus on eligibility and referral criteria was felt to be helpful for referring programs.

## Commitments and Implementation

Health providers at the Forum shared and discussed their experiences from their own programs. These are included here, in their own words, as part of guiding the implementation of recommendations in this report.

- *“Provincial health authorities, Organ Donation Organizations, and CKD clinics all need to be on side.”*
- *“Shifting the care pathway to put transplant first is an important assist, as are standardized and trackable metrics.”*
- *“Cultural norms and traditions can influence potential recipients in powerful ways: indigenous recipients are inclined to not engage with the system and look instead to their elders for advice and approval.”*
- *“I feel more permission to take an active approach with those looking for a living donor. We have a real opportunity to help build confidence and engage more with potential transplant candidates and I’m looking forward to doing so.”*
- *“We’re going to spend less time talking to people on dialysis about iron and phosphate levels, and more time talking about living donor transplants. It’s time for us to present this as the ‘Cadillac’ treatment earlier and more often.”*

- *“I’m going to explore the feasibility of having donor/transplant ambassadors in our clinic. We could be using peer mentors to do more – culturally sensitive ambassadors would be a powerful aid.”*
- *“It is clear that social workers are critical to success in this. I’m going to explore having them more involved on my team.”*
- *“We’re going to continue our work at the national level to coordinate and support these efforts.”*
- *“We created a schism between our dialysis and transplant worlds – it is time we changed our referral and evaluation processes and involved the whole team. A culture of transplant first means we need to include those providing CKD and dialysis care process.”*
- *“Our program has a taboo about using social media – we’re going to educate coordinators and staff that we can do this in an appropriate way.”*
- *“First and foremost, a culture shift needs to take place across the board, from CKD to dialysis, so all staff are on board and in the same place. We also need standardized material for both donors and recipients.”*
- *“Encourage patients bring as many people as possible with them to meetings. Not necessarily to ask them to donate, but to make them aware of the opportunity and the change it would make in the life of their loved one.”*

## Donor and Recipient Insights

The participating donors and transplant recipients provided vital contribution to the Forum. Their stories motivated and inspired everyone in the room. When asked for any insights and reflections on the Forum, the following comments were offered:

*From transplant recipients:*

- *“We need to support the donors early and by checking in throughout the process, to see if they are still on board. It’s easy for donors to put off that thinking until they’re assessed.”*
- *“I felt left out having to check on my first donor. I felt guilt putting that pressure on them. It’s a lot easier to be given information than to have to find it yourself.”*
- *“I was surprised how disconnected the processes are within each region. When I heard about some hospitals assessing one person and others five, that was an eye opener – there isn’t equity across the country.”*



- *“I’ve met a number of people who donated and went into deep depression post-donation but didn’t ask for help – and there was no support for them. There are a lot of the soft elements of the process that could be improved.”*
- *“This may be one of the hardest things a person may go through – to know they need someone else to save their lives.”*

From donors:

- *“There’s an awful lot of pressure on the recipient to get a donor. Let’s not forget they’re very ill, and quite foggy, their self-worth is low, and they don’t necessarily have the strength to be proactive. They need help and encouragement, not just information.”*
- *“Some don’t truly reflect on their offer to donate and back out down the road. In the meantime, they have delayed the next person waiting, and the recipient is getting sicker. How can we make sure people are genuine with their intentions at an earlier stage?”*
- *“It shouldn’t be on the person who is sick to be responsible for pushing the donor, checking on them, and making sure they keep up with their appointments. But it is. Letting recipients know it’s not all their responsibility would be helpful.”*

## Meeting Reviews

Meeting participants expressed great appreciation for the opportunity to participate in this meeting. Not only was the in-person meeting very helpful for putting faces to names and providing opportunities for networking, the following sentiments about the success of the meeting were included in the “other comments” section of the meeting evaluation form:

- *“Really enjoyed meeting the community in person and collaborating on how we can help each other better. Thank you for inviting me.”*
- *Excellent - feeling very inspired.”*
- *“Wonderful event. Generated a fantastic amount of meaningful conversations. I have a few tangible opportunities that I believe will have an impact right away. I am really anticipating the draft report and the opportunity to share with staff & organization.”*
- *“Meet with managers to get stakeholders buy in, engage patient family committee to explore transplant ambassador program. Reach out to programs who have materials to share with our program.”*
- *“Thank you for this amazing experience. This forum was the most useful to me for learning in my 35 years of nursing. Hands down :)!! Thank you for allowing me to participate.”*

- *“I am hopeful about the ongoing work on advancing LD transplant and CBS' ability to coordinate the work going forward.”*

## Next Steps

Canadian Blood Services held another forum in 2019 that focused on defining the requirements for a single, national living donor registration portal. The report contains recommendations that the portal include a repository of educational information on living donation. Ideas generated at the Advancing Living Donation Forum reinforce the necessity for that portal, and, importantly, the need for national standardized materials.

Canadian Blood Services is committed to an ongoing and long-term focus on increasing living donation rates in Canada. The recommendations from this Forum will help guide new and ongoing initiatives aimed at advancing, improving and increasing living kidney donation.

Dr. Sunita Singh, Chair of the Forum Planning Committee, thanks participants for their time and energy. She felt it was a terrific Forum and extremely beneficial to hear and learn from such a diversity of perspectives.

Dr. David Landsberg, Vice-Chair of the Forum Planning Committee said the meeting had exceeded his expectations and that he was happy to hear that people were working together toward a common goal. He thanked donors and recipients for sharing their voices – noting that he had attended many meetings, and this was the first time he had seen such natural patient engagement – and extended his appreciation, on behalf of everyone, to the organizers for making the event possible.

## Appendix I: Forum Overview

A Steering Committee with broad representation from Canadian living donation and transplant programs was formed (see Appendix 1). Chaired by Dr. Sunita Singh, the committee, assisted by an external facilitator from Strachan-Tomlinson, developed the process, prepared background materials and reviewed and gave final approval for the recommendations developed at the Forum.

The process was designed to bring together as wide a range of perspectives as possible to build recommendations for Canada. The 54 participants included living kidney donors, kidney transplant recipients, nephrologists of varying subspecialties (transplant, living donation, chronic kidney care clinic, dialysis, community nephrology), social workers, living donor coordinators, pre-transplant coordinators, pharmacists, an ethicist, a transplant ambassador coordinator, a modality education nurse, dialysis nurses, and an Aboriginal liaison coordinator.

The forum opened with presentations from a kidney transplant recipient, a living kidney donor, and clinical experts, followed by a question and answer session. Participants were seated in groups of mixed clinical perspectives, with either a living kidney donor or kidney transplant recipient at each table. Discussions took place in small and large group settings, with pre-defined worksheets to be completed to build the recommendations.

### Welcome Address

An emphasis during the forum was on the need to help patients help themselves. The goal was to develop actionable recommendations that can be shared with Canadians in need of a kidney transplant, as well as the care providers who help them along their journey of care. The participants were selected to represent a broad community of care for patients with chronic kidney disease and kidney failure, and as such, will have the opportunity to advocate and champion the recommendations with their peers and their programs.

This Forum is one of a set of complementary initiatives being led by Canadian Blood Services to advance living kidney donation and transplantation, which include the development of an on-line Living Donor Registration Portal (LDRP) for potential donors to be able to find information about living donation and to begin the registration and potentially the evaluation process, and the development of a network of Living Donation Program managers, coordinators and quality assurance personnel to allow the community to collaborate, solve challenges and share best practices to optimize living kidney donation at all programs. Additionally, Canadian Blood Services operates the Kidney Paired Donation Program for Canada that increases living kidney donor transplant opportunities for patients who have a willing but medically incompatible living donor. The donors help their incompatible pair by participating in a chain of donor swaps so that all the candidates receive a medically suitable living donor kidney transplant.

With more than 3,200 patients on the waiting list for a kidney transplant as of December 31, 2018, and some 100 dying each year, there is a critical need to help to close the gap between demand for kidney transplants and donor availability by increasing living donation.

## Challenge Address

Dr. David Landsberg, Co-Chair of the Forum Steering Committee and Chair of LDAC provided the challenge address. He noted that while deceased donation had seen successes in the past, living donation has remained relatively flat, saying “the time has come for us to reinvest and drive living donation forward”.

He presented data showing the advantages of receiving a living donor kidney transplant over chronic dialysis therapy, if transplantation is a medical option for the patient. LDKT has a strong survival advantage over chronic dialysis therapy even in carefully selected, high-risk groups. Those who receive living donor kidney transplants enjoy better quality of life (at a lower cost to the health system) than those transplanted from dialysis.

Dr. Landsberg pointed to significant regional variations in the living donation rate as opportunity for significant gains. For example, in British Columbia the living donation rate per million population was well above the national average and is in some regions comparable to the highest rates internationally.

Some of the factors contributing to the success of the living kidney donation program at his hospital (St. Paul’s Hospital in Vancouver) include: funding and cultural support for living donation, dedicated social workers trained in living donor education and outreach, working up multiple donors for a transplant candidate simultaneously, a strong emphasis on participating in the Kidney Paired Donation (KPD) program with a healthy but medically incompatible donor, and a responsive surgical group that gives pre-emptive transplants a high priority.

The final message of his address was that pursuing “Living Donor Kidney Transplant First” was not a challenge to be afraid of but one to be pursued. Since shifting its efforts in this direction, British Columbia’s pre-emptive transplant rate has risen to 35-40 percent of their kidney transplants and the number of living donors in the province is steadily moving upward. His final message: “What are we afraid of? Humans are generous by nature – we just need to do a better job of asking!”

## Panel Discussion: Sharing Experience

Following Dr. Landsberg’s address, participants heard from three separate perspectives.

**Dale Orton** took part in a paired exchange program after volunteering to donate a kidney to a friend. He described a positive overall experience in which he felt well informed, had empathy and support from the nurses and transplant staff, and the helpful opportunity to speak to someone who had already been through the procedure.

Mr. Orton also mentioned a sense that many who decide to donate do so with little contemplation or reflection, and that they may reconsider further into the living donation assessment process. He also discussed how difficult it was to travel to another province for surgery.

**Stephen Case** received a living donor kidney transplant in August 2019. As a private person, it was only through the intervention of a family member that a donor came forward.

Mr. Case said he had felt well educated throughout the process and that his only recommendation was to discuss the paired exchange program first, as many patients ruled themselves out of being able to find a living donor because they mistakenly thought they had to

have a donor with the same blood type. He mentioned that his attitude towards living donation had changed over the course of the process, and that he was glad someone had championed his cause to others.

Transplant nephrologist **Dr. Shaifali Sandal** presented highlights of her recent research<sup>4</sup> on health professional-identified barriers to living donor kidney transplantation, noting that the focus tends to be on patient/recipient barriers to donation, but that there are other barriers at the referral, transplant centre, and system levels. These include health professionals' uncertainty about interventions, cost, difficulties for people of lower socio-economic status, and the onus being placed on those who are sick (e.g., on dialysis) to help themselves by finding a living donor.

Many health professionals felt they didn't have adequate information or training and were not comfortable discussing living kidney donor transplantation with patients. Dialysis nurses were in the best position to discuss LDKT with patients, but two thirds didn't feel comfortable doing so. Some health professionals were not providing the appropriate information to their teams or to patients, and there were patient-level barriers as well (e.g., stigma, language and cultural differences, age, substance use, etc.) that may be contributing to low LDKT rates.

## Research Overview

Dr. Sunita Singh, Medical Director of the Living Kidney Donation Program at Toronto General Hospital, presented an overview of the background research reviewed by the Forum Steering Committee with a focus on initiatives aimed at increasing living kidney donor transplantation rates.

For patients, the main barriers identified in the research are:

- lack of education on LDKT for patients and families
- lack of public awareness about LDKT
- financial barriers (e.g., out of pocket costs, lost wages), to living kidney donors and
- health-care system level barriers (e.g., lengthy evaluation process, recipients becoming ineligible during the donor evaluation process; patients opting-out of pursuing living donation due to process issues).

From the Health Professional's perspective, the barriers include:

- lack of communication between CKD clinics, dialysis units and transplant teams
- the absence of referral guidelines; lack of clarity around roles and responsibilities for sharing information
- lack of training and information about LDKT
- misinformation and myths amongst health care providers around LDKT and

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<sup>4</sup> Sandal, S., Charlebois, K., Fiore, J. F., Wright, D. K., Fortin, M.-C., Feldman, L. S., ... Weber, C. (2019). Health Professional-Identified Barriers to Living Donor Kidney Transplantation: A Qualitative Study. *Canadian Journal of Kidney Health and Disease*. <https://doi.org/10.1177/2054358119828389>

- patient-level barriers as described above.

Dr. Singh noted the potential for modifying these barriers and described tested interventions in education, the evaluation process, and related to social media.

Education strategies that have been proven effective at increasing patient knowledge relating to LDKT included: house calls to provide information to recipients and their families and friends, sessions with social workers (at home or in the transplant centre), targeted and culturally sensitive information sessions, patient navigators (social workers) in community nephrology clinics, weekend seminars, and the recruitment of living donor champions. Several educational strategies are also being tested in Canada include ongoing work with the [Explore Transplant Ontario Program](#) and the Enhance Access to Kidney Transplantation and Living Kidney Donation (EnAKT LKD) study being led by Dr. Amit Garg.

Streamlining the evaluation process for potential donors has also been tested with some success. In Northern Ireland, the adoption of a one-day donor assessment model supported a sustained increase to LDKT rates. In the U.S., the use of web-based screening increased the number of self-referrals. Dr. Singh noted that Canadian Blood Services is developing a national, online donor registration portal to serve a similar purpose.

Social media is another area of promise: Twitter and Facebook are being used by donors and health professionals to share stories and research and to find living donors. A study on the impact of a Facebook app used by transplant centres to help transplant candidates find living donors and a donor champion showed not only a shorter time to first donor referrals but also a much greater likelihood (6.6 times) of a living donor coming forward. Important considerations around social media included the need for a level of technological capability and legal and ethical issues related to fairness, privacy, and coercion.

## Appendix II: Forum Participants

### Steering Committee

**Dr. Sunita Singh, Chair; MD, MSc, FRCPC**



Dr. Sunita Singh is a transplant nephrologist in the Division of Nephrology and the medical director of the living kidney donation program at the Toronto General Hospital, University Health Network. She is also an Assistant Professor of Medicine at the University of Toronto. Dr. Singh completed medical school at the University of Toronto, and internal medicine and chief medical residency at the University of British Columbia. She returned to Toronto to complete a Master of Science in clinical epidemiology and health care research, as well as additional fellowship training in kidney transplantation and advanced diabetes care. Dr. Singh's research interests are focused on the evaluation and follow-up of living kidney donors, as well as the management of diabetes in kidney transplant recipients.

**Dr. David Landsberg, Vice-chair; MD**



Dr. David Landsberg is a transplant nephrologist. He did his nephrology and transplant training at the University of Toronto. He moved to UBC in 1984 and established a new kidney transplant program at St. Paul's Hospital in Vancouver. He is the chair of the Living Donor Advisory Committee, Canadian Blood Services. He is a passionate advocate for transplantation and living donation.

**Dr. Ann Bugeja, MD, FRCPC**



Dr. Ann Bugeja completed her medical degree, internal medicine and nephrology training at the University of Toronto. She is an Assistant Professor of Medicine at the University of Ottawa. She is the lead for the Living Kidney Donation and In-Centre Nocturnal Hemodialysis Programs at The Ottawa Hospital with clinical research interests in these areas. Dr. Bugeja is also involved with mentorship and education and received the 2017 Undergraduate Teaching Award at the University of Ottawa.

**Dr. Sandra Cockfield, MD**



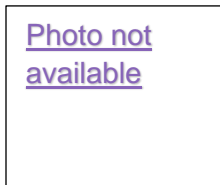
Dr. Sandra Cockfield received her both her undergraduate and medical degrees from the University of Toronto. After completing residency training in general internal medicine and nephrology in Toronto, she joined the laboratory of Dr. Philip Halloran for a research fellowship focused on the regulation of MHC expression and its relationship to cytokine gene expression in a variety of murine models. She joined the Faculty of Medicine at the University of Alberta in 1990 and is currently a Professor in the Division of Nephrology and Transplantation Immunology at the University of Alberta. She has served as Residency Program Director (1993-1999), Clinical Program Director of the Northern Alberta Renal Program (1998-2002) and is currently the Medical Director of the Renal Transplant Program and the Living Donor Program.

**Ms. Maureen Connelly, RN BSc**



Maureen Connelly is a Living Kidney Donation Coordinator at St. Michael's Hospital Transplant Program in Toronto, Ontario. Maureen has extensive nursing experience in kidney transplantation and living kidney donation as well as critical care and emergency/trauma. She has presented at national and international conferences. She has shared her expertise in consulting roles with Trillium Gift of Life Network, the Ontario Ministry of Health, the Kidney Foundation, the Canadian Counsel of Donation & Transplantation and Canadian Blood Services. She was part of the original team to initiate the Kidney Paired Donation protocol between St. Michael's and Toronto General Hospital prior to the option becoming a national reality. She has been a member of the CBS Living Donor Advisory Committee since its inception and was a contributor to the CBS Kidney Donor Protocol.

**Dr. Christine Dipchand, MD, FRCPC**



Professor of Medicine, Nephrology, Dalhousie University. Interests are Living Kidney donation. Christine is a member of the Living Donor Advisory Committee and is the Medical Director of living kidney donation for Multi-organ Transplant Program in Atlantic Canada.

**Dr. Amit Garg, MD, PhD, FRCPC, MA, FACP**



Dr. Amit Garg is the Director of their Living Kidney Donor Program at the London Health Sciences Centre where he also provides nephrology care to patients in multi-care kidney clinics and hemodialysis units. He recently co-Chaired the new International KDIGO Clinical Practice Guidelines in Living Kidney Donation and serves as the Medical Lead for the Ontario Renal Network to Enhance Access to Kidney Transplantation and Living Kidney Donation in Ontario. He is well versed in transplant and living kidney donor records in large provincial databases, and is the Lead for the Ontario ICES Kidney, Dialysis and Transplantation (ICES KDT) Program. He has research experiences to



share, with over 80 peer reviewed publications in living kidney donation (which has featured in the NEJM, Lancet, Ann Intern Med, J Am Soc Nephrol, Am J Transplant and other leading medical journals). As a Professor of Medicine, Epidemiology and Biostatistics at Western University, he is funded for living kidney donor research by the federal government and other sources. He has served on the Canadian Blood Services, Living Donor Advisory Committee since its beginning.

**Dr. Rahul Mainra**, BSc, MD, MMed, FRCPC



Dr. Rahul Mainra is a Transplant Nephrologist working in the Division of Nephrology at St. Paul's Hospital in Saskatoon, Saskatchewan. He is the director of UGME for the Department of Medicine at the University of Saskatchewan. He is the current vice-chair of the Kidney Transplant Advisory Committee.

**Ms. Ruth McCarrell**, RN BSN



Ruth has had a long nursing career with over sixteen years as the Clinical Nurse Leader for the Living Kidney Donor and Kidney Recipient Pre-Transplant Programs at St. Paul's Hospital, Vancouver, BC. She has been a key advisor on many provincial and national committees including as a working member of the Canadian Blood Services' Living Donation Advisory Committee.

**Dr. Michel Pâquet**, MD, Ph.D., FRCP(C)

(Add Picture)

Dr. Michel Pâquet is a Transplant Nephrologist and Medical Director of the Kidney Living Donation Program at CHUM, Montréal. He is an Assistant Professor at the Université de Montréal and the Medical Advisor for Living Donation & Transplantation at Canadian Blood Services.

**Mr. Clay Gillrie**, RN, BSN, MSN; Senior Program Manager, Living Donation and Transplantation, Canadian Blood Services, Vancouver, BC

**Ms. Charley Bekolay**; Program Associate, Living Donation and Transplantation, Canadian Blood Services, Edmonton, AB

**Dr. Janice Bissonnette**, RN, PhD; Senior Program Manager, Living Donation and Transplantation, Canadian Blood Services, Edmonton, AB

**Mr. Mike Tomlinson**, Facilitator; Strachan-Tomlinson, Ottawa, ON

**Ms. Kathy Yetzer**, B.Comm, BSc.(Pharm); Associate Director, Living Donation and Transplantation, Canadian Blood Services, Edmonton, AB

**Ms. Jenny Ryan**, BA (Hons); Manager, Program Operations, Organ and Tissue Donation and Transplantation, Canadian Blood Services, Ottawa, ON

## Forum Participants

Ms. Sadia Baig, BSW; Programs Coordinator at the Kidney Foundation of Canada and on dialysis, Mississauga, ON

Dr. Mike Bevilacqua, MD, FRCPC; Medical Lead for the Polycystic Kidney Disease Network for the BC Renal Agency and Clinical nephrologist in Fraser Health Authority, BC

Ms. Fannie Blanchet; Living Donor Kidney transplant recipient, Cumberland, BC

Mr. Stephen Case; Living Donor Kidney transplant recipient, Toronto, ON

Dr. Marie Chantal-Fortin MD, Ph.D., FRCP(C); Principal Scientist Division of Nephrology, CHUM Research Centre, Montreal, QC

Ms. Candice Coghlan; Living Donor Kidney transplant recipient, Kitchener, ON

Ms. Jana Costa, RN; KPD and HSP Transplant Coordinator, Foothills Medical Centre, Calgary, AB

Dr. Olivier Diec, MD; Community Nephrologist, Hospital Charles Lemoyne, President of South Shore Branch of Quebec Kidney Foundation, Montreal, QC

Ms. Lindsey Doxtator; Program Manager, Kingston Health Sciences Centre, Kingston, ON

Dr. Kathy Ferguson, MD; Community Nephrologist, Moncton NB

Ms. Arlene Funnell, RN; Recipient Coordinator, Kingston Health Sciences Centre, Kingston, ON

Ms. Melissa Giroux, RN, CNE; Chronic Kidney Disease Clinical Nurse Educator, Edmonton AB

Ms. Julie Gratton-Edwards RN, BN; Living Donor Kidney Coordinator, Winnipeg Health Sciences Centre; Winnipeg, MB

Ms. Tricia Hutton, BSW, RSW; Medical Social Worker Hemodialysis Unit, Saskatoon, SK

Ms. Carolyn Jarvis MFA, BFA, BSW; Social Worker, Vancouver, BC

**Dr. Olwyn Johnston**; Medical Director Kidney and Pancreas Transplant; Vancouver General Hospital Transplant Nephrologist; Gordon and Leslie Diamond Centre, Vancouver, B.C.

Dr. Bruce Jones MD; Community Nephrologist, Charlottetown, PEI

Ms. Leslie Jones; Report Writer, Ottawa, ON

Dr. Joanne Kappel, MD, FRCP(C); Head Division of Nephrology for the College of Medicine and Dyad Co-Lead for Kidney Health Services, Saskatoon, SK

Mr. Dani Khanafer; Senior Policy Analyst, Health Canada, Ottawa, ON

Dr. Ngan Lam, MD, FRCP(C), MSc; Associate Professor, Division of Nephrology, University of Calgary, Calgary, AB

Ms. Lydia Lauder; Kidney Foundation of Canada Representative, Toronto, ON

Dr. Darius Lazarus MD; Nephrology Specialist, Centre intégré de santé et des services sociaux de l'Outaouais, Gatineau, QC

Dr. Sarah MacDonald, MD; Transplant Nephrologist, Gatineau, QC

Ms. Lisa Martin RN; Living Donor Kidney Coordinator, Queen Elizabeth II Health Sciences Centre, Halifax, NS

Dr. Sean Martin MD, BSc ; Community Nephrologist, NFL

Ms. Jessica McDougall, RN, BScN, MN; Living Donor Kidney Coordinator, The Ottawa Hospital, Ottawa, ON

Dr. Matthew Miller, MD, BSc, FRCP(C); Living Donor Nephrologist, St Joseph's Healthcare Hamilton, Hamilton, ON

Ms. Beth Montesi, RN; Living Donor Coordinator, London Health Sciences Centre, London, ON

Mr. Dale Orton; Living Kidney Donor, QC

Ms. Andrea O'Shaughnessy, RN, BSN; Recipient Coordinator, Vancouver General Hospital, Vancouver, BC

Ms. Glenda Peebles; Aboriginal Liaison Coordinator for the Manitoba Renal Program and a living kidney donor for her sister, MB

Dr. Shaifali Sandal, MD, FRCP(C); Transplant Nephrologist, McGill University Health Center, Montreal, QC

Ms. Christina Schellenberg; Renal Social Worker, Vancouver, BC

Dr. Khaled Shamseddin, MD, MSc, FRCP(C); Associate Professor of Medicine and Transplant Nephrology  
Director, Kidney Transplant Program; Director, Napanee Dialysis Clinic Kingston General Hospital, Kingston, ON

Ms. Nancy Sparrow, RN, CNeph(C); Transplant Coordinator, Pre-emptive and Independent Dialysis Programs, Trafalgar Memorial Hospital, Oakville, ON

Ms. Lori Van Manen, RN BSN; Program Operational Director, Renal and Palliative Care Service, Kingston Health Sciences Centre, Kingston, ON

Ms. Valentina Vexelshtein, RN; Registered Nurse Kidney Care Clinic, Mackenzie Health, Richmond, ON

Ms. Angela Wishnowski, RN, BScN, CNeph(C); Pre-Renal Transplant Coordinator, University of Alberta Hospital, Edmonton, AB

Ms. Janet Wright; Living Donor Kidney Recipient, Toronto, ON

## Appendix III: Acronyms and Definitions

### Acronyms

CKD	Chronic Kidney Disease
ESKD	End Stage Kidney Disease
LDKT	Living Donor Kidney Transplant
LDAC	Living Donation Advisory Committee
LDKT	Living Donor Kidney Transplant
LKD	Living Kidney Donation
OTDT	Organ and Tissue Donation and Transplantation

### Definitions

LDAC	<i>LDAC includes representatives from all of Living Donation Programs in Canada and provides strategic and operational oversight and advice related to living kidney donation in Canada. <a href="https://professionaleducation.blood.ca/en/organs-tissues/program-overview/living-donation-advisory-committee-ldac">https://professionaleducation.blood.ca/en/organs-tissues/program-overview/living-donation-advisory-committee-ldac</a></i>