

Workshop Report:  
Identifying Best Practices and Ways to Increase the use of  
Living Donor Kidney Transplantation in Alberta

---

Kidney Health Strategic Clinical Network™

December 2, 2015

For more information on this report, contact [kidneyhealth.scn@ahs.ca](mailto:kidneyhealth.scn@ahs.ca)

## Executive Summary

### Background issue

Each year in Alberta, over 500 people develop end-stage renal disease requiring renal replacement therapy (i.e., dialysis or transplantation), or conservative care management. Despite the fact that kidney transplantation is the optimal therapy for eligible patients and for health care payers, 19 of 20 Albertans under the age of 60 commence dialysis, rather than receive a kidney transplant. The number of people receiving kidney transplants in Alberta over the past ten years has been stable despite a 40 percent increase in the number of people with end stage renal disease. Recognizing that there are many barriers to increasing the number of living donor kidney transplants, a one-day workshop to better understand the barriers to living donor kidney transplantation in Alberta was convened by the Kidney Health Strategic Clinical Network™, Alberta Kidney Care, and the Northern and Southern Alberta Transplant Programs.

### The purpose of this report

This report provides a summary of the proceedings of this one-day workshop whose objectives were to:

- Review the number and types of transplants occurring in Alberta, by program and zone
- Determine current practice and the related resources consumed by kidney transplantation in Northern Alberta Renal Program and Southern Alberta Renal Program
- Share best practices between transplant programs on ways to increase the use of living donor kidney transplantation
- Identify ways to increase the use of living donor kidney transplantation in Alberta by exploring barriers faced by donors, recipients and providers and identifying potential ways to address these barriers
- Determine the feasibility of implementing identified strategies to overcoming barriers to living donor kidney transplantation in Alberta
- Identify potential stakeholders interested in participating in a Kidney Health Strategic Clinical Network™ Living Donor Kidney Transplant Working Group

### Highlights of Workshop discussion

A series of presentations outlining current research, the current state of living donor kidney transplantation across Canada, and current Canadian initiatives directed at improving the rates of living kidney donation were shared with workshop participants. The speakers included two patients who provided their detailed personal accounts of the barriers and successes they experienced in their respective journeys along the pathway to kidney transplantation.

The preliminary results of an Alberta-wide survey “**Identifying the best practices and ways to increase the use of living donor kidney transplantation in Alberta**” were presented. This survey examined barriers to living donor kidney transplantation from the perspectives of patients, potential donors, and health care providers. The preliminary results of this survey demonstrated that:

- (1) Educational materials for potential donors and recipients are limited and incomplete
- (2) Recipients and donors are generally not well-informed on the potential risks and benefits of kidney transplantation and donation
- (3) The financial burden of donation remains a barrier - up to one third of all donors remain unaware of programs that provide financial support

From the proceedings of the Living Donor Kidney Transplant workshop, it is clear that there is opportunity to

- (1) Develop more comprehensive web-based, interactive, and video media versions of educational materials for recipients and donors.

- (2) Increase the conversion rate of the potential donors to actual donors by providing better education and support for Kidney Paired Donation
- (3) Better inform and support potential donors about available financial reimbursement programs
- (4) Improve satisfaction with the donor and recipient assessment processes by decreasing variability and improving care across the province

### Next steps

Building on this workshop and related research, a collaborative working group supported by, and reporting to, the Kidney Health Strategic Clinical Network™ will be established. The first meeting of this group will be in March 2016. Membership will include representatives from all key stakeholder groups involved in living donor kidney transplantation in Alberta. This group will be responsible for

- (1) Identifying priority initiatives related to overcoming barriers to living donor kidney transplantation in Alberta
- (2) Developing strategies and clear implementation plans to address agreed-upon priorities
- (3) Working with key stakeholders, inclusive of chronic kidney disease (CKD) clinics and dialysis units to implement operational plans agreed upon by Alberta Kidney Care North and South to increase the number and rate of living donor kidney transplantation for both adults and children with kidney failure in Alberta
- (4) Supporting implementation plans, changes, and evaluation of changes including key performance indicators to measure successes to program delivery
- (5) Working with other national stakeholders (e.g., Canadian Blood Services, and the Ontario Renal Network™) who have living donor initiatives underway
- (6) Identifying relevant performance indicators, recommending measurement strategies, monitoring living donor kidney transplant activity and patient/family satisfaction in Alberta and reporting on progress towards objectives
- (7) Improving equity of access to living donor kidney transplantation and minimizing geographic and population inequities in Alberta
- (8) Improving patient satisfaction with the transplant workup process through patient and family centered processes

The Living Donor Kidney Transplant working group will draft a comprehensive plan to be implemented in collaboration with Alberta Kidney Care and Alberta's transplant programs with the intent of addressing barriers to living donor kidney transplantation and increasing the use of living donor kidney transplantation.

**Contents**

Executive Summary..... 1

    Background issue ..... 2

        The purpose of this report ..... 2

        Highlights of Workshop discussion ..... 2

        Next steps ..... 3

Background ..... 5

Overview of preliminary work ..... 6

Overview of Survey ..... 7

    Principal Investigators:..... 7

    Purpose ..... 7

    Respondents ..... 7

    Preliminary Survey Findings..... 7

Proceedings of the workshop: ..... 9

    Workshop attendees:..... 9

    Presentation Summaries..... 9

    Small group sessions ..... 13

    Summary Notes and Group Session Feedback ..... 14

Next Steps in addressing barriers to Living Donor Kidney Transplantation ..... 18

Conclusions ..... 18

References:..... 20

Appendix 1: Workshop agenda and speakers..... 20

Appendix 2: Workshop Participants ..... 24

## Background

Each year in Alberta, over 500 people develop end-stage renal disease requiring renal replacement therapy (i.e., dialysis or transplantation), or conservative care management (i.e. supportive non-dialysis care). Persons under the age of 60 usually choose a form of renal replacement therapy<sup>1</sup>. Of this group, 19 of every 20 patients start therapy with dialysis while one in 20 receives a pre-emptive transplant. These apparent preferences for renal replacement therapy are made even though 8.4% of people on dialysis who are under the age of 60 die each year, and despite the fact that patients receiving dialysis experience very poor quality of life, compared with kidney transplantation<sup>2,3</sup>.

Kidney transplantation, while not a cure for kidney disease, is the optimal therapy for eligible patients with advanced kidney failure. Transplantation improves survival and quality of life in comparison to dialysis<sup>3,4</sup>. For these same reasons, and because it reduces healthcare costs, kidney transplantation is also the preferred treatment for advanced kidney failure for healthcare payers<sup>1,5,6,7,8</sup>.

There are two main types of kidney transplantation, deceased and living donor transplantation. Living donor transplantation, where an eligible donor (either related or unrelated to the recipient) donates a kidney to the recipient, has advantages over deceased donor transplantation since the donated organ lasts longer than one from a deceased donor, and because living donor transplants can be obtained much more quickly. In Alberta, for patients without a living donor, wait times for a deceased donor transplant exceed seven years, and many patients will die waiting for a deceased donor transplant. While there are differences in the number of transplants completed across the different Alberta Health Services (AHS) zones, living donor transplantation could be used more frequently by patients with kidney failure in Alberta<sup>1</sup>.

Canadian Blood Services<sup>9</sup> reports Alberta's living kidney donation rates under the Kidney Paired Donation program to be average when compared to the nine other Canadian provinces. Key performance indicators including the number of living donors, candidates for living kidney donation, and the percentage of candidates receiving a kidney transplant are reported at the national and provincial level for the ten Canadian provinces. For the five-year period, 2011 – 2015, British Columbia ranked highest among all of the provinces on measures of

- the number of living donor kidneys per million population,
- the number of kidney paired donation candidates per million population,
- the percentage of kidney paired candidates receiving a transplant.

Based on these same measures and in comparison to the other nine Canadian provinces, Alberta ranks fifth, fourth, and sixth respectively for the five year period 2011 – 2015.

Navigating the pathway to receive a living donor kidney transplant is complex. Patients and donors are required to undergo comprehensive physical, laboratory, and radiological assessments. They must attend numerous appointments, meet all of the medical requirements and most importantly, find a compatible donor. Research has identified a number of barriers to successful living donor kidney transplantation, including emotional and cultural barriers experienced by both recipients and potential donors<sup>5</sup>. Given the “nonmedical” nature of these barriers, health care providers may not always understand their importance or significance.

Waterman et al<sup>6,10</sup> identified that recipients may experience fears for both themselves and the donor. These same authors have shown that feelings of guilt are pervasive among potential recipients. Recipients often identify that it is difficult to talk about donation and it is even more difficult to approach potential donors<sup>10</sup>.

Potential living donors may experience concerns about personal safety, and difficulties with meeting the comprehensive demands of completing a full living donor work-up due to competing time commitments inclusive of family and employment. Faith, cultural, and financial barriers (including the need to take time away from work which may not be compensated) are also known to affect one's decision to donate<sup>5</sup>.

After a thorough discussion of the issues above, the operational leads of Alberta Kidney Care, the Northern and Southern Alberta Renal Programs (NARP and SARP respectively), the Northern and Southern Alberta Transplant Programs, and the Kidney Health Strategic Clinical Network<sup>TM</sup> (KH SCN<sup>TM</sup>) identified increasing living kidney transplantation through better understanding of barriers to living kidney donation as a key area for consideration.

This report summarizes the proceedings of the workshop, including an overview of the current state of provincial and national living donor transplant initiatives, preliminary results of an Alberta-based survey identifying perceived barriers to living kidney donation for both donors and recipients, and an overview of interactive discussions that focused on three key topics:

- Strategies to address the barriers faced by recipients.
- Strategies to address the barriers faced by donors.
- Learning from each other's best practices

Finally, a discussion of future directions, including formation of a working group within the Kidney Health Strategic Clinical Network<sup>TM</sup> is provided.

## Overview of preliminary work

Alberta Kidney Care (AKC), in conjunction with the Kidney Health Strategic Clinical Network<sup>TM</sup> (KH SCN<sup>TM</sup>), established a steering committee to plan and deliver the workshop. Co-chaired by the Interim Scientific Director of the KH SCN<sup>TM</sup>, and the Medical Directors of Alberta's transplant programs, it also included representatives of Alberta Kidney Care. The goals of the workshop were to:

- review the number and types of transplants occurring in Alberta, by program and zone
- determine current practice and the related resources consumed by kidney transplantation in Northern Alberta Renal Program and Southern Alberta Renal Program
- identify perceived barriers to living donor kidney transplantation
- identify strategies to increase living donor kidney transplantation,
- determine feasibility of implementation of identified strategies
- identify ways to optimize the medical evaluation of potential living kidney donors and recipients

After several meetings of the steering committee, a final agenda for the workshop was agreed upon, and a list of speakers was identified (Appendix 1). The steering committee identified a need to conduct a survey to better understand the barriers experienced by potential recipients and donors, and to elicit the feedback of healthcare professionals regarding barriers to living donor kidney transplantation. Two transplant Nephrologists (Doctors Shojai and Lam) modified existing validated transplant surveys<sup>6</sup>, and coordinated survey administration, in conjunction with the KH SCN<sup>TM</sup> and the transplant programs.

## Overview of Survey “Identifying the best practices and ways to increase the use of living donor kidney transplantation in Alberta”.

**Principal Investigators:** Soroush Shojai MD & Ngan Lam MD MSc, Assistant Professors of Medicine, Division of Nephrology and Transplant Immunology, University of Alberta

**Purpose:** To identify the most common and impactful barriers faced by potential kidney transplant recipients and living kidney donors in Alberta. The validated Living Donor Kidney Transplant Concerns questionnaire authored by Waterman<sup>2</sup> and adapted with permission to the Alberta context was administered to potential recipients undergoing or completed their transplant workup, to potential donors undergoing or completed their workup, and to Health Care Providers who care for potential recipients or potential donors. The survey was administered between October 2015 and December 1, 2015.

### Respondents

Response rates along with demographic characteristics of donor and recipient respondents are listed in Table 1 below.

Table1: Preliminary Survey respondent details:

Baseline Characteristics	Edmonton				Calgary				Total			
Health Care Providers	113 (48 % response)				45 (18 % response)				158 (33 % response)			
<b>Donors &amp; Recipients</b>												
	Donors		Recipients		Donors		Recipients		Donors		Recipients	
Total Responses	N=32 (18.29 % response)		N=53 (8.31 % response)		N=49 (14 % response)		N=13 (1.81 % response)		N=81 (15.4 % response)		N=66 (4.8 % response)	
Age - Mean (in years)	48.5		57		49		62.5		49		58	
Gender	N	%	N	%	N	%	N	%	N	%	N	%
Male	8	25	30	56	14	29	6	46	22	37	36	55
Female	22	69	20	38	33	67	6	46	55	68	26	39
No response*	2	6.3	3	5.7	2	4.1	1	7.7	4	4.9	4	6.1

\* when asked about gender, survey respondents could select “male”, “female”, or “other”. A number of respondents did not provide a response under “gender” within the survey

### Preliminary Survey Findings

Acknowledging that the response rates were small (particularly for recipients from Calgary), the findings herein offer a preliminary insight into barriers to donation and living donor kidney transplantation within Alberta.

Respondent Demographics showed that the majority of the potential Donors are female (70%), almost one third of the Donors have income below the provincial average and one third live more than two hours away from an assessment centre.

Potential recipients' responses indicated that:

- (1) Educational materials are limited and web-based and video media versions are required.
- (2) Recipients are not generally well-informed on the potential risks and benefits of kidney transplantation not only to themselves but also to their potential donors (85 percent were unaware or underestimated the peri-operative risk to donors).
- (3) The lack of advocacy for recipients, the inability to communicate their needs with others and reaching wider community were also noted as barriers to pursuing living donor kidney transplantation.

Potential living donor respondents, like recipients, indicated educational materials are limited and web-based and video media versions are required.

- (1) All respondents indicated they donated to make someone's life better and to allow recipient to live longer and free of dialysis;
- (2) Approximately 90 percent of all respondents donated to benefit family and friends.
- (3) Of all respondents, 60 percent indicated a spiritual or personal belief was part of their motivation to serve as a donor.

Based on the preliminary survey findings, it would appear that potential living kidney donors need to be better-informed with up-to-date information on the donation risk. Living donors' knowledge needs to be assessed to ensure informed consent has been received. The financial burden associated with donation is still a barrier to donation, therefore donors need to be better-informed about available reimbursement programs (one third are still unaware of this support); the majority of living donors need help and support.

Satisfaction with the assessment process varies across the province and should be improved. Seventy percent of donors indicated they would be willing to enter a paired donation program. Fifty-five percent of those responding they would enter the paired exchange program suggested they would be willing to wait for greater than two years to donate. This indicates that there is a significant opportunity to increase the conversion rate of the potential donors to actual donors by providing better education and support for Kidney Paired Donation.

Preliminary review of staff responses to the survey point to a need for strategies supporting recipients to effectively communicate their needs and approach potential living donors, educate the healthcare community, recipients, potential living donors and society about living donor kidney transplantation, and streamline the assessment process.



## Proceedings of the workshop:

### Workshop attendees:

Workshop attendees included seven patient advisors (inclusive of recipients, potential and anonymous donors, and a parent of a child recipient), five transplant Nephrologists, two transplant surgeons, five general nephrologists, four living donor coordinators, three pre-transplant and recipient coordinators, 16 transplant program administrators, two Kidney Foundation of Canada representatives, two representatives from Canadian Blood Services, and seven representatives from the Kidney Health SCN™. Attendees were from across Alberta. A full list of workshop attendees is available in Appendix 2.

### Presentation Summaries

A brief overview, including key messages where possible, of each of the presentations is provided below. For more information on the specific presentations, please contact the Kidney Health SCN™ at [kidneyhealth.scn@ahs.ca](mailto:kidneyhealth.scn@ahs.ca).

(1) Alberta Landscape: Alberta Kidney Care (Kailash Jindal)

Key messages:

- Alberta Kidney Care Coordinating Council was recently established to coordinate services offered by the Alberta Kidney Care

(2) Alberta Landscape: Kidney Health Strategic Clinical Network™ (Louise Morrin and Nairne Scott Douglas)

Key messages:

- Provided an overview of the Kidney Health Strategic Clinical Network™ including its mandate, details associated with its official launch in January 2016, and its role in supporting the advancement of donation and transplantation in Alberta

(3) Alberta Landscape: The Numbers: Alberta versus Canada (Braden Manns)

Key messages:

- There are at least eight Canadian initiatives intended to support and improve rates of transplantation currently underway
- The number and type (living donor, paired donor, cadaverous donor) of organ donation in Alberta and between Zones for the past 10 years was compared across Alberta zones and regions
- Differences in the rates of kidney transplantation were noted between Alberta zones, and it was noted that the Northern Alberta Transplant program consistently performed more transplants than the Southern Transplant program (because of a higher number of deceased donor transplants)
- The number of living donor kidney transplants is similar across the Northern and Southern Alberta Renal Programs.
- Controlling for the size of the province, Alberta is performing roughly the same number of transplants as Ontario

(4) Alberta Landscape: Transplant Program Processes (Soroush Shojai)

Key messages:

- outlined a series of similarities and differences in the donor work-up processes between the Alberta Transplant programs
- a series of linear steps to donation in each program were identified

- The Calgary-based program requires a potential donor to complete a minimum of 11 encounters with the healthcare system to complete the donation process; the Edmonton-based program requires potential donors to complete a minimum of 13 encounters to complete the donation process

Conclusion: there is a need to streamline the donation process, make it patient-centered, and advocate for more on-line resources to remove a number of current barriers to donation

#### (5) Alberta Landscape: Transplant Program Resources

##### Part 1: Resources Supporting Living Donor Transplantation in Northern Alberta Renal Program (NARP) (Sandra Cockfield)

Key messages:

- The WAVE pilot project with the Canadian Institute for Health Information (CIHI) demonstrated that NARP had an average wait time that exceeded the national average on measures of time of referral to time of nephrologist assessment and on time of referral to patient disposition (though in part this was due to measurement issues)
- For the period January 2013 – December 2014 approximately 60 percent of all referrals proceeded to see the transplant nephrologist
- For the period January 2014 – December 2014, NARP received 267 donor calls; 206 proceeded to donor evaluation process; 18 underwent donor nephrectomy highlighting that nearly 10 donors begin workup for everyone who donates

##### Part 2: ALTRA, Southern Alberta Transplant Program (Lee Anne Tibbles)

Key messages:

- The prevalence of pre-transplant kidney patients is growing annually
  - exceeded 200 referrals in 2014/2015
- the prevalence of post-transplant patients for kidney patients approached 900 patients in 2014/2015
- The number of living donor kidney transplants, exclusive of the paired donation program is decreasing over the past three years; the number of living donors in work-up for donation or waiting kidney paired exchange has continued to grow at a steady rate since 2011/2012

#### (6) Patients Journeys Through the System

- Two patients shared their journeys through their journey of kidney failure, dialysis, donor and recipient work-ups, and the transplant experience
- They identified system challenges and offered insight into areas for improvement

#### (7) Canadian Initiatives: a scoping review and CNTRP update

##### Part 1: Scoping review key messages (Scott Klarenbach)

Key messages:

- The current state of research related to Living Kidney Donation between 1997 and 2014 was reviewed; there are few studies examining the impact of living donor interventions and there is opportunity to examine the impact of a variety of interventions
- It was noted that patient education (particularly when occurring in a home setting) may be effective in increasing living donor transplantation

## Part 2: Canadian National Transplant Research Program updates (Lori West)

### Key messages:

- Supporting research in a broad range of topics within transplantation across all organ types in Canada
- Gathering the evidence, making it accessible to wider audiences, working together to inform policy
- Patient engagement strategy to improve the research and to involve patients and families at all stages of the research
- Goals are to
  - increase the availability of donors and access to transplants
  - extend the longevity of grafts
  - improve long-term survival and quality of life of transplant patients

### (8) Canadian Initiatives: Ontario Living Donor Initiative (Istvan Mucsi)

#### Key messages:

- The likelihood of kidney transplantation is highest among Caucasians.
- Barriers such as decreased health literacy, psychological and ethno cultural factors play a role in low transplant and donor rates
- Changes to donor and recipient education, including the new Explore Transplant comprehensive education suite, is being piloted in Ontario with the goal of increasing living donor transplantation

### (9) Canadian Initiatives: Canadian Blood Services Kidney Program (Kimberly Young)

#### Key messages:

- History and progress of the Paired Donation program was reviewed
- Kidney Paired Donation rates in Alberta rank below a number of provinces
  - British Columbia ranks first on all measures provided
- A number of challenges to increasing the success of the Kidney Paired Donation program in Alberta were reviewed

### (10) Updates and recent developments in Alberta (Marilyn Bartoszyk)

- Changes to patient Education in Chronic Kidney Disease Clinics
  - A new provincial Treatment Options Pathway for educating patients with Advanced CKD about their treatment options (including the different types of dialysis, transplantation and conservative non-dialysis care)
  - While intended to inform choice of treatment, the current group education does not focus on transplant, and additional education opportunities are required for transplant.

### (11) Donor Risks – what patients need to know (Ngam Lam)

#### Key messages:

- A summary of the research related to morbidity and mortality in living kidney donors was provided
- The evidence shows there to be a small increased risk in pregnancy-related complications and a small increased risk of End Stage Renal Disease for donors after twenty years.
- Based on analysis of 12 different studies, the risk of living kidney donors developing End Stage Renal disease was one in 200 (0.5%) over a 20-year period living kidney donors have a relative increased risk of End Stage Renal Disease compared to healthy non-donors; The absolute 15-year incidence of End Stage Renal Disease in living donors is less than one percent
- The evidence shows no difference in mortality to donors on measures associated with cardiovascular disease, fractures, gastro-intestinal bleeding,

(12) Barriers – a review of the literature (Ngam Lam)

Key messages

Transplant education, ethno-cultural differences in transplantation and Living Kidney Donation, lack of efficiency in the Living Kidney Donation process, and economic challenges for donors

- Conclusions: barriers to Living Kidney Donor processes affect donors, recipients, transplant centers and Provincial and National policies.

(13) Preliminary Results of an Alberta Survey (Soroush Shojai)

The key messages and findings are outlined earlier in this report

## Small group sessions

In the afternoon, participants were engaged in a World Café intended to elicit feedback from all participants on the barriers and strategies to overcome these barriers associated with living donor kidney transplantation. Participants were assigned to a series of small groups consisting of eight to ten participants each. Facilitators and content experts (nurses and Nephrologists from transplant programs) led each of the small groups.

The World Café was structured such that each contributor was given an opportunity to identify and concentrate on each of the specific questions and themed areas listed below.

The three topics along with the specific questions participants were asked to answer were:

**(1) Strategies to address the barriers faced by recipients.**

- What challenges do recipients face in identifying a living donor?
- How can we help recipients overcome these challenges in identifying a living donor?

**(2) Strategies to address the barriers faced by donors.**

- What prevents living donors from coming forward?
- How can we make it easier for living donors to come forward?

**(3) Learning from each other's best practices**

- What strategies can be used to improve communication?
- How can shared learning be supported between the programs?
- How should the work-up process be optimized?

During the interactive discussions at each station of the World Café, facilitators transcribed key conversation points (noted in the tables below). Upon the conclusion of the small groups, participants were asked to prioritize (using a system of placing dots on priority concepts) the three most important barriers and strategies for further consideration – highlighted in the tables below in bold.

## Summary Notes and Group Session Feedback

The barriers and strategies associated with living kidney donation identified by the contributors are outlined in the tables below. Those topics, strategies, and areas that were deemed as priorities through the voting process are presented in bold type within the tables.

### Question 1: Strategies to address the barriers faced by Recipients.

Barriers Identified	Strategies Identified (top priority strategies are listed in bold)
Cultural differences in transplantation and beliefs about transplantation <ul style="list-style-type: none"> <li>• Lack of educational materials in other languages</li> </ul>	Create resources in multiple languages  Consider cultural differences when supporting potential recipients and living donors
Knowledge <ul style="list-style-type: none"> <li>• Lack of available education materials</li> <li>• Lack of details</li> <li>• Lack of Information about living donor options – paired exchange</li> <li>• Lack of accurate information on risks to living donor and recipient</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Home transplant education</b></li> <li>• <b>Family education</b></li> <li>• <b>Cultural appropriate education</b></li> <li>• <b>National approach</b></li> <li>• <b>On-line educational website</b></li> <li>• <b>Peer support</b></li> </ul>
Recipients comfort in approaching or seeking out a potential living donor due to: <ul style="list-style-type: none"> <li>• Guilt – rejection episode</li> <li>• Stigma of organ donation</li> <li>• Revealing health status</li> <li>• How to Screen potential living donors</li> </ul>	<b>Forum for potential living donors</b> <ul style="list-style-type: none"> <li>• <b>Pros/cons of donation</b></li> </ul> <b>Friend/family champion</b>  <b>Skill building for recipients</b> <ul style="list-style-type: none"> <li>• <b>Start conversations early</b></li> <li>• <b>Letter writing</b></li> </ul> <b>Donor advocate – to train how to network to find living donor</b>  Peer support - creation of patient/family support groups (share common experiences, express concerns, learn from each other)
Impact on future relationship with family/ living donor if: <ul style="list-style-type: none"> <li>• Potential donor declines</li> <li>• Donor not eligible</li> <li>• Transplant fails</li> </ul>	Education <ul style="list-style-type: none"> <li>• Develop information and strategies for living donors on ways to tell a recipient they are not a match; for recipients to approach family/friends to be potential living donors</li> </ul>
Finances (especially if living donor and recipient in same family)	<b>Financial support</b> <b>Increase awareness of currently available financial support</b>

## Question 2: Strategies to address the barriers faced by Living Donors

Barriers identified	Strategies (top priority strategies are listed in bold)
Time Restrictions	<ul style="list-style-type: none"> <li>• <b>Fewer visits (use other visit methods where possible (phone, etc.))</b></li> <li>• <b>Bundle appointments</b></li> <li>• <b>Central access point for living donors to reduce confusion around process</b></li> </ul>
Financial	<ul style="list-style-type: none"> <li>• <b>Worker protection for individuals who take time off work to donate a kidney</b> <ul style="list-style-type: none"> <li>○ <b>Maternity leave concept</b></li> </ul> </li> <li>• <b>KFOC program – advertise that a program exists to reimburse living donor expenses</b></li> <li>• <b>Develop a program that compensates living donors who are undergoing testing</b></li> <li>• Find ways to promote transplant in Alberta's political agenda</li> </ul>
Geographic	<ul style="list-style-type: none"> <li>• Utilize technologies (telehealth, etc.) as much as possible to reduce the number of visits required</li> </ul>
Lack of Awareness of living kidney donation, particularly among friends, and other unrelated donors	<ul style="list-style-type: none"> <li>• <b>Better public website (including information for living donors on process, risks, financial assistance), chat room</b></li> <li>• Better information on donating beyond family members</li> <li>• <b>Registry of living donors who might consider donating altruistically</b></li> </ul>
Lack of Knowledge	<ul style="list-style-type: none"> <li>• Improve education, better understanding of risks</li> <li>• <b>Provider education in advance of formal visit</b></li> <li>• Improve access to information (on-line)</li> <li>• Access to 3<sup>rd</sup> party as trusted source of information (e.g. KFOC)</li> <li>• <b>Home-based education</b></li> <li>• Measure success/outcomes of education</li> </ul>
Communication issues: <ul style="list-style-type: none"> <li>• Between Patients/Provider               <ul style="list-style-type: none"> <li>• What do patients need to know?</li> </ul> </li> <li>• Provider to Provider               <ul style="list-style-type: none"> <li>• Recipient to potential living donors</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <b>Build skills, give tools for patients to speak to family, potential living donors</b></li> <li>• e-mail policy – resolve encryption issues</li> <li>• MyHealthAlberta patient portal – on line questionnaire to determine eligibility</li> <li>• Platform for sharing provincially</li> </ul> <p>Feedback - provide mechanisms for anonymous feedback on experiences with the work-up process</p>

<p>Lack of Public Campaign</p>	<p><b>Public Campaign</b></p> <ul style="list-style-type: none"> <li>• For example, Brazilian buries car, or ice bucket challenge</li> </ul> <p>Political advocacy – increase awareness of costs (from dialysis as opposed to transplant) and benefits to patient and system</p> <p>Need to educate public about benefits of transplant (dispel myths on risks/benefits of donation; education about life on dialysis)</p>
<p>Access to information on where living donors and recipients are at within the workup</p> <ul style="list-style-type: none"> <li>• Are recipients/donors on list, and if not why not?</li> <li>• What still needs to happen?</li> </ul>	<p>Develop a seamless tool so that patients can track where they are at in their workup, and what remains to be done</p> <p>This system could still enable confidentiality across donor and recipient workup.</p>
<p>Complex and intense process</p>	<ul style="list-style-type: none"> <li>• <b>Map process, identify redundancies, smooth the process</b></li> <li>• <b>Standardize the process, consistent policies and guidelines – inter- and intra- provincial</b></li> <li>• <b>Navigator or concierge or case manager (consistent point person assigned to patient (living donor and recipient)</b></li> <li>• <b>Bundle appointments</b></li> <li>• <b>Better coordinate recipient and living donor workup</b></li> <li>• <b>Process too linear – look at what can be done simultaneously</b></li> </ul>



The World Café stations that focused on learning from best practices across transplant programs, expressed a common interest in annual meetings to share policies, procedures, and best practices. In addition, several health care provider and health system barriers were noted to living kidney donation, particularly relating to use of kidney paired exchange and pre-emptive transplant. Included in the behaviours and practices were a lack of awareness of these programs and lack of understanding of the importance of pre-emptive transplant. At the level of the health system, several important barriers were noted, including a lack of good quality data to measure health system performance relevant to living donor kidney transplantation, and lack of coordinator resources and other resources to expedite workup.

### Question 3: Learning from each other's best practices

Barriers Identified	Strategies Identified (top priority strategies are listed in bold)
Health Care Providers – lack of information about or importance of: <ul style="list-style-type: none"> <li>• Kidney paired exchange</li> <li>• Pre-emptive transplant</li> </ul>	Increase Awareness through staff events <ul style="list-style-type: none"> <li>• As occurs with “Home sweet Home dialysis”</li> <li>• CKD nurses advocate</li> </ul>
Health System <ul style="list-style-type: none"> <li>• Lack of good quality data on how we are doing</li> <li>• Lack of resources</li> <li>• Lack of sharing of best practice across the province</li> </ul>	<ul style="list-style-type: none"> <li>• Annual Sharing Meetings between the North and South transplant program               <ul style="list-style-type: none"> <li>○ Leverage technology to enable sharing of policies, procedures, and educational tools</li> </ul> </li> <li>• <b>Provincial data repository, data sharing between programs</b></li> <li>• <b>Quality indicators/Key performance indicators to allow us to know where the problems are</b></li> <li>• Annual report with broad dissemination – including front line staff               <ul style="list-style-type: none"> <li>• Identify what resources are most needed to impact problem</li> </ul> </li> </ul>
Inability to identify best practices across Canada	<ul style="list-style-type: none"> <li>• Identify leaders in living donor transplant, and determine how their program / education is structured               <ul style="list-style-type: none"> <li>○ BC has very high living donor transplant rates – Why?</li> </ul> </li> </ul>
Complex and intense workup process for living donors and recipients	<ul style="list-style-type: none"> <li>• <b>Map process, identify redundancies, smooth the process</b></li> <li>• <b>Standardize the process, consistent policies and guidelines – inter- and intra- provincial</b></li> <li>• <b>Bundle appointments</b></li> <li>• <b>Better coordinate recipient and donor workup</b></li> <li>• <b>Process too linear – look at what can be done simultaneously</b></li> <li>• Develop national registry – support local donor identification programs through creation of national website for living donors to commence pre-screening questionnaire</li> </ul>

## Next Steps in addressing barriers to Living Donor Kidney Transplantation

Building on the work and findings from the December 2, 2015 workshop, a Transplant working group within the Kidney Health SCN™ will be established. The first meeting of this new working group will be convened in March 2016. Participants at the December workshop were invited to indicate their interest in participating in this working group. Membership will consist of:

- Patient advisors
- Canadian Blood Services
- Alberta Kidney Care
- Alberta Kidney Foundation
- North and South Transplant program clinical and administrators
- North and South Transplant program coordinators
- North and South Transplant surgeons and nephrologists
- Kidney Health Strategic Clinical Network™

The group will report to the KH SCN™ Core Committee and will be responsible for

- (1) Identifying priority initiatives related to overcoming barriers to living donor kidney transplantation in Alberta
- (2) Developing strategies and clear implementation plans to address agreed-upon priorities
- (3) Working with key stakeholders, inclusive of chronic kidney disease (CKD) clinics and dialysis units to implement operational plans agreed upon by Alberta Kidney Care North and South
- (4) Supporting implementation plans, changes, and evaluation of changes including key performance indicators to measure successes to program delivery
- (5) Working with other national stakeholders (e.g., Canadian Blood Services, and the Ontario Renal Network) who have living donor initiatives underway
- (6) Identifying relevant performance indicators, recommending measurement strategies, monitoring living donor kidney transplant activity and patient/family satisfaction in Alberta and reporting on progress towards objectives
- (7) Improve equity of access to living donor kidney transplantation and minimize geographic and population inequities in Alberta
- (8) Improve patient satisfaction with the transplant process through patient and family centered processes

## Conclusions

For eligible people with advanced kidney failure, kidney transplantation represents a significant improvement in quality and length of life. It is also the most cost effective form of renal replacement therapy for both patients and health care payers. Although the current rate of living donor kidney transplantation in Alberta is in keeping with other Canadian jurisdictions (e.g., Ontario), there is a clear need to address barriers affecting rates of living donor kidney transplantation in Alberta.

Many of the barriers to living donor kidney transplantation identified locally and internationally were confirmed and expanded upon in this one-day workshop and within the Alberta-based survey of recipients, donors, and care providers. During the course of this one-day workshop, recipients, donors, and health care providers achieved consensus on the need to overcome barriers to living kidney donation and on the need to develop and implement plans specifically tailored to

- streamline the donation process for potential donors and recipients,
- improve content and access (e.g., on-line content) to educational materials for both donors and recipients
- address financial barriers to living donation

- effectively plan for a public campaign increasing the awareness and importance of living kidney donation and the paired donation program

Through the Living Donor Kidney Transplant working group, reporting to the Core Committee of the Kidney Health Strategic Clinical Network<sup>TM</sup>, a comprehensive plan will be drafted and implemented over the course of the next several months with the intent of addressing many of these barriers to living donor kidney transplantation and increasing the use of living donor kidney transplantation.

## References:

1. Kidney Strategic Clinical Network™ (April 1, 2015). Prevalence of severe kidney disease and use of dialysis and transplantation across Alberta from 2004 – 2013.
2. US Renal Data System. *USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States.* Bethesda, MD: National Institutes of Health.
3. Laupacis, A., Keown, P., Pus, N., Krueger, H., Ferguson, B., Wong, C., & Muirhead (1996). A study of the quality of life and cost-utility of renal transplantation. *Kidney International*, 50, 235 – 242.
4. Wolfe R, Ashby V, Milford E, Ojo A, Ettenger R, Agodoa L, et al. (1999) Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant *New England Journal of Medicine*, 341, 1725-30
5. Rodrigue, J.R., Paek, M.J., Egbuna, O., Waterman, A.D., Schold, J.D., Pavlakis, M., & Mandelbrot, D. A. (2014, December). Readiness of wait-listed black patients to pursue live donor kidney transplant. *Progress in Transplantation*, 24 (4), 355 – 361.
6. Waterman, A.D., Robbins, M.L., Paiva, A.L., Peipert, J.D., Kynard-Amerson, C.S., Goalby, C.J., Davis, L.A., Thein, J.L., Schenk, E.A., Baldwin, K.A., Skelton, S.L., Amoyal, N.R., and Brick, L.A. (2014). Your path to transplant: a randomized controlled trial of a tailored computer education intervention to increase living donor kidney transplant. *Biomed Central Nephrology*, 15, 166 – 179.
7. Waterman, A.D., Robbins, M.L., Paiva, A.L., Peipert, J.D., Davis, L.A., Hyland, S. S.S., Schenk, E.A., Baldwin, K.A., & Amoyal, N.R. (2013, October). Measuring kidney patients' motivation to pursue living donor kidney transplant: development of stage of change, decisional balance, and self-efficacy measures. *Journal of Health Psychology*, 0 (0), 1 - 12.
8. Institute for Health Economics (2015). Innovative funding models. Kidney care policy options for the future.
9. Young, Kimberly (December 2, 2015). *Canadian Blood Services Canadian Initiatives: Canadian Blood Services Advancing Living Donation.* Presented to Identifying Best Practices and Ways to Increase the use of Living Donor Kidney Transplantation in Alberta, Leduc, AB.
10. Roberts, K. F. (1998). *Federal regulations of chemicals in the environment* [PowerPoint slides]. Retrieved from <http://siri.uvm.edu/ppt/40hrenv/index.html>
11. Waterman, A.D., Barrett, A.C., & Stanley, S. L. (2008, March). Optimal transplant education for recipients to increase pursuit of living donation *Progress in Transplantation*, 18 (1), 55 – 62.
12. Rodrigue, J.R., Paek, M.J., Egbuna, O., Waterman, A.D., Schold, J.D., Pavlakis, M., & Mandelbrot (2014, November 15). Making house calls increases living donor inquiries and evaluations for blacks on the kidney transplant waiting list. *Transplantation*, 98 (9), 979 – 986.

## Appendix 1: Workshop agenda and speakers

### Identifying Best Practices and Ways to Increase the use of Living Donor Kidney Transplantation in Alberta

Sponsored by the Kidney Strategic Clinical Network™, Alberta Kidney Care, Northern Alberta Transplant Program and the Alberta Renal Transplant Program

Executive Royal Hotel, 8450 Sparrow Drive  
Leduc, Alberta T9E 7G4  
Lancaster A Conference Room

**December 2, 2015 (9:15am – 3:40pm)**

#### Workshop Objectives:

- To identify ways to increase the use of Living Donor Kidney Transplant by exploring barriers faced by donors, recipients and providers and to identify potential ways to address them.
- To share best practices between transplant programs on ways to increase the use of Living Donor Kidney Transplantation.
- To identify potential stakeholders interested in participating in a Transplant Working Group within the Alberta Health Services Kidney Health Strategic Clinical Network™.

<b>9:00am – 9:15am</b>	<b>Registration and Light Morning Snack</b>	All
<b>9:15am – 9:45am</b>	<b>Introductions and Overview of the Day</b> <ul style="list-style-type: none"> <li>• Alberta Kidney Care</li> <li>• Kidney Strategic Clinical Network™</li> </ul>	Braden Manns Kailash Jindal Louise Morrin and Nairne Scott-Douglas
<b>9:45am – 10:45am</b>	<b>The Alberta Landscape - Living Kidney Donor Transplantation</b> <ul style="list-style-type: none"> <li>• The Numbers: Alberta versus Canada</li> <li>• Transplant Program Processes</li> <li>• Transplant Program Resources</li> <li>• A Patient's Journey Through the System</li> <li>• Q &amp; A / Group Discussion</li> </ul>	Braden Manns Soroush Shojai Sandra Cockfield and Lee Anne Tibbles Linda All
<b>10:45am – 10:55am</b>	<b>Break</b>	All
<b>10:55am - 12:00pm</b>	<b>Updates and Recent Developments in Alberta</b> <ul style="list-style-type: none"> <li>• Canadian Initiatives:               <ul style="list-style-type: none"> <li>- Strategies to increase living donor transplantation - a scoping review (CNTRP)</li> </ul> </li> </ul>	Braden Manns Lori West and Scott Klarenbach

	<ul style="list-style-type: none"> <li>- Ontario Living Donor Initiative</li> <li>- Canadian Blood Services Kidney Program</li> </ul>	Istvan Mucsi Kim Young
<b>10:55am - 12:00pm</b>	<b>Updates and Recent Developments in Alberta (continued)</b> <ul style="list-style-type: none"> <li>• Changes to Patient Education in Alberta's Chronic Kidney Disease Clinics</li> <li>• Donor Risks – What patients need to know</li> <li>• Q &amp; A / Group Discussion</li> </ul>	Marilyn Bartoszyk & Kin Tan Ngan Lam All
<b>12:00pm – 1:00pm</b>	<b>Light Lunch</b>	All
<b>1:00pm – 1:50pm</b>	<b>Perceived Barriers to Living Donor Transplantation</b> <ul style="list-style-type: none"> <li>• A Review of the Literature</li> <li>• Results of an Alberta Survey</li> <li>• Patient Reflections on Barriers Experienced</li> <li>• Q &amp; A / Group Discussion</li> </ul>	Braden Manns Ngan Lam Soroush Shojai Bonnie All
<b>1:50pm – 2:00pm</b>	<b>Break</b>	All
<b>2:00pm – 3:00pm</b>	<b>Small Group Sessions</b> <ul style="list-style-type: none"> <li>• <b>Groups 1 &amp; 4: Strategies to address the barriers faced by donors.</b> <ul style="list-style-type: none"> <li>- What prevents living donors from coming forward?</li> <li>- How can we make it easier for living donors to come forward?</li> </ul> </li> <li>• <b>Groups 2 &amp; 5: Strategies to address the barriers faced by recipients.</b> <ul style="list-style-type: none"> <li>- What challenges do recipients face in identifying a living donor?</li> <li>- How can we help recipients overcome those challenges in identifying a living donor?</li> </ul> </li> <li>• <b>Groups 3 &amp; 6: Learning from each other's best practices</b> <ul style="list-style-type: none"> <li>- What strategies can be used to improve communication?</li> <li>- How can shared learning be supported between the programs?</li> </ul> </li> </ul>	Susan Sobey (lead facilitator) <u>Group#1 Facilitator:</u> Gloria Hodder <u>Group #4 Facilitator:</u> Susan Sobey <u>Group #2 Facilitator:</u> Obianuju Mollel <u>Group #5 Facilitator:</u> Tracey Geyer <u>Group #3 Facilitator:</u> Louise Morrin <u>Group #6 Facilitator:</u> Terry Smith

	- How should the work-up process be optimized?	
<b>3:00pm – 3:10pm</b>	<b>Break</b>	All
<b>3:10pm – 3:30pm</b>	<b>Small Group Sessions Feedback Review</b>	Susan Sobey and Group Leads
<b>3:30pm – 3:40pm</b>	<b>Next Steps and Closing Remarks</b>	Braden Manns and Louise Morrin

## Appendix 2: Workshop Participants

<u>NAME</u>	<u>TITLE</u>
Anita Kozinski	University of Calgary
Bonnie Corradetti	Patient Rep.
Braden Manns	Interim Scientific Director, KH SCN™
Cheryl Davis	Pre-Transplant Coordinator, Calgary
Christina Parsons	Sr. Program Manager, Living Donation , Donation & Transplantation, Canadian Blood Services (Edmonton)
Dalena McLeod	Patient Rep.
Deana Paulson	Executive Director, NARP and Transplant Services
Flavia Robles	Kidney Foundation of Canada
Gerald Todd	Transplant Surgeon
Gloria Hodder	Consultant - Knowledge Management (Facilitator)
Istvan Mucsi	Transplant Nephrologist - University Health Network, Toronto
Jana Costa	Living Donor Coordinator, Calgary
Janice McKenzie	Renal insufficiency lead NARP, Administrative Lead
Jeffrey Ma	Nephrology – Fellow
Jill Goth	Manager, Programs & Organ Donation Initiatives - KFC
Joan Caskey	Patient Rep.
Joyce Van Deurzen	Executive Director, Kidney Foundation of Canada
Kailash Jindal	Zone Clinical Section Chief , Renal and Medical Lead, NARP
Karley Cronk	Living Donor Coordinator, Edmonton
Kathy Yetzer	Associate Director, Living Donation, Donation & Transplantation - Canadian Blood Services (Edmonton)
Kelly Peloquin	Quality Assurance Coordinator - Transplant Services
Kim Worton	Unit Manager HOPE / Living Donor programs
Kevin Wen	Transplant Nephrologist, University of Alberta
Kimberly Young	Director, Donation & Transplantation, Canadian Blood Services
Kin Tam	Renal insufficiency lead SARP, Administrative Lead
Leanne Gosse	Pre-Transplant Coordinator, Kidney, Calgary
Lee Anne Tibbles	Director of ALTRA Transplant Program
Linda Soltys	Patient Rep.
Lori West	Director of the Alberta Transplant Institute (ATI)
Louise Morrin	Senior Provincial Director, KH SCN™
Marilyn Bartoszyk	Manager, SARP
Mike Bentley	Patient Care Manager, Transplant Services, Edmonton
Mike Simoens	Patient Rep.



Nairne Scott-Douglas	KH SCN™ Senior Medical Director & AHS Zone Clinical Section Chief , Renal and Medical Lead, SARP
Ngan Lam	Transplant Nephrologist, University of Alberta
Obianuju Mollel	Consultant - Knowledge Management (Facilitator)
Phil Bobawsky	Patient Rep.
Rob Quinn	Renal insufficiency lead SARP, Medical Director
Sandra Cockfield	Medical Director, Renal Transplant Program & Director, Living Donor Kidney Program, Edmonton
Sandi Vanderzee	Incoming Director, Northern Alberta Renal Program
Scott Klarenbach	Nephrology – UAH
Serdar Yilmaz	Transplant Surgeon
Sherri Kashuba	Managing Director, Alberta Organ and Tissue Donation Agency, Alberta Health
Sherry Buckle	Unit Manager of the Southern Alberta Renal Transplant Program
Soroush Shojai	Transplant Nephrologist, University of Alberta
Sue McKenzie	Transplant Recipient & Senior Director Development, The Kidney Foundation of Canada
Susan Sobey	Senior Planner, Planning & Performance
Tania Woodlock	Patient Rep.
Tasleem Rajan	ALTRA Transplant Nephrology
Teresa Trottman	Living Donor Coordinator, Calgary
Terry Smith	Manager, Kidney Health SCN™
Toni Chow	Pre Renal Transplant Coordinator for Northern Alberta Renal Transplant Program
Tracey Geyer	Senior Health Planner, Planning & Performance
Tracy Ross	Living Donor Coordinator, Calgary
Tracy Schwartz	Patient Care Manager, NARP
Trudie Yeung	Recipient Coordinator, Edmonton
Shelagh Dupuis (Admin Support)	Executive Administrative Assistant - Kidney Health SCN™