

## Kidney Transplant & Finding a Living Donor

Thursday, October 1, 2020, 3 – 5 pm (PT)

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#### Kidney Transplant & Finding a Living Donor

Welcome to patients, persons considering being a living donor, families, loved ones and staff members!

Purpose: To talk about:

- Transplant as a treatment option
- Finding a living donor
- Being a living donor

Goal: To provide information to help discussions with your Kidney Care/Transplant Team





#### Housekeeping



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- **General** questions are welcome throughout the presentation! Please discuss questions **specific** to your situation with your Kidney Care/Transplant Team.
- To ask a question:
  - Click/tap on Q&A
  - Type in your question and press enter. This will send your question to the presenter
  - When there is a break in the presentation, the presenter will respond to questions
- After the session you will be asked to complete a feedback form
  - Please complete this form to make our sessions even better!



#### Overview of presentation

- Welcome & Introductions Dr. Mike Bevilaqua
- Kidney Transplant Recipient Program
  - Who is eligible? What are the transplant options?
  - What is the process?
  - Kidney Recipient's Experience
- Living Kidney Donor Program
  - How can someone donate?
  - What is the donor assessment like?
  - Living Kidney Donor's Experience



#### Modality planning in the current environment

- Usually these discussions take place in a very different way
  - Face-to-face, group sessions, encouraged to have family/loved ones present
- This session supplements but does not replace conversations with your kidney care/transplant team
  - The goal is to provide an overview, food for thought
  - Then please bring this back to the team at your home clinic to discuss how this applies to you/your loved ones
- If you told us when you registered that it was okay, we will let your home team know you attended today so they can follow up with you





#### Importance of planning ahead

- Kidneys provide vital functions and their failure leads to complications
  - If this does happen, many different options are available for management of kidney failure

# What is important to you, what works best for your life

- Determine this plan in advance while there is no urgency, time to think, discuss with loved ones
  - More important now than ever before





#### Introduction of the VGH Transplant Team

- Kidney Transplant Recipient Program
  - Who is eligible? What are the transplant options?
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#### **BC Kidney Transplant Stats**

#### www.transplant.bc.ca

#### Number of Kidney Transplants in BC by Donor Type



revincial Health Services Authorit

#### **Kidney transplantation....**

Is it the right treatment for me? Do the benefits out weigh the ris Renefits of transplant

- Feel better / have more energy
- Freedom from dialysis
- Greater independence / free to travel
- Increased life expectancy
- Regular diet
- Risks of transplant
  - Surgical Procedure
  - Eg: bleeding, infection, anesthesia
    Medications weaken your immune system
    More prone to infections

    - More prone to some cancers



#### **Referral Process**

- Referred by primary nephrologist
  - Preferably when GFR is 20-25
- Primary Nephrologist and GP continue to act as primary caregivers
- Referral does not mean you are on the waitlist for a transplant. You must be assessed first



#### **Assessment Process**

- Initial workup and preliminary education is completed by referring center
- Testing may include:
- Bloodwork
- Heart diagnostics
- Chest x-ray
- Dental check up
- Baseline cancer screening (FIT/colonoscopy, Pap smear/ mammogram for females, prostate exam for males)
- Infectious disease screening and vaccinations



#### Assessment Process- Clinic Visit

- When basic tests are completed, a patient can be booked for transplant clinic.
- A clinic visit includes appointments with...
  - The transplant physician
  - The transplant surgeon
  - Social Worker
  - Nurse
  - Additional staff as deemed necessary



#### Assessment process -Clinic Visit

Your waiting time for a clinic appointment will depend on...

- Whether you have a potential live donor
- Blood type and the anticipated waiting time for your blood group



#### The approval process

 All investigations are reviewed by the entire team, you will be...

- Approved
- Declined
- Asked to complete further testing
- Length of Process depends on medical conditions, tests required and availability of appointments
  - Time to transplant will depend on donor options and blood type



#### Approved for transplant. Now what?

**Pre-Dialysis** 

- Live donor transplant when GFR <15
- Deceased donor waiting list when started on dialysis

- On Dialysis
  - Deceased donor waitlist
  - Live donor transplant



## Why Living Donation?

- Benefits for Recipient:
  - Kidney lasts longer with living donation
  - Avoid the waiting list
  - Potential for pre-dialysis transplant
  - More opportunity to plan ahead for transplant
  - Greater control over personal/professional life



#### **Deceased Donor WAITLIST**

- Wait time for deceased donor transplant is affected by:
  - Blood type
     A
     D
     2-3 years
     B
     4-5 years
     AB
     1-2 years
  - Dialysis start date
  - Changes to a recipient's health status
    - Temporarily placed on hold for new medical issues or travel
  - Level of sensitization if any



#### Are you sensitized

- A donor's blood type must be suitable for you
- Blood testing predicts whether a particular donor's kidney can be safely transplanted. This is checked before a living donor or deceased donor transplant is confirmed.
- You may be harder to match (more sensitized) because of a past:
  - Blood transfusion
  - Pregnancy
  - Transplant
  - Serious infection



#### What is your Role/responsibility?

- Manage lifestyle factors:
- Optimize your health so you are ready for transplant
- Maintain healthy, active lifestyle
  - Healthy weight
  - Optimal diabetic control
  - Smoking cessation
- Once referred, keep transplant center informed of:
- New medical concerns
- Seeing a new Health Care Provider / Specialist
- Admission to hospital
- Change of address and contact numbers



#### **Recipient Transplant Surgery**

- Surgery takes about 3 hours
- Original kidneys left in place
- Transplanted kidney placed low in abdomen near bladder





#### What to expect post Transplant

- In hospital for 5-7 days
- Assessed frequently and anti-rejection drugs started
- Recipient stays in Vancouver for up to 3 months posttransplant
- Once stable: transferred to a Post-Transplant clinic closer to home

**Note:** Home Team and Transplant Team social workers will assist with planning for transplant



#### **Graft Failure / Rejection**

#### Acute rejection

- When immune system attacks the kidney
- Occurs in 10-15% of patients in the 1<sup>st</sup> year
- Responds well to treatment
- <u>Does not mean you will lose your kidney</u>
- Chronic Rejection
  - Slow, progressive decrease in graft function
  - Reasons are less understood

(average lifespan of a kidney transplant is 16 years)



# TRANSPLANT RECIPIENT EXPERIENCE



## Questions and Answers for Recipient Team



# LIVING KIDNEY DONOR PROGRAM



## Living Donor Program

- Provides education and testing for donors
- Commits to safe outcomes
- Supports a donors' decisions
- Maintains confidentiality



#### **Living Donation Principles**

- Voluntary decision
- Free from coercion
- Donor sets the pace of the assessment
- Informed consent is an ongoing process during workup
- Right to withdraw or stop testing at anytime



#### Who Can Be a Kidney Donor?

- Family Members
- Friends, acquaintances, work colleagues
- NOTE: By participating in the Kidney Paired Donation Program, you can help a loved one or friend get a kidney transplant even if you can not directly donate to them.



# Possible Reasons for Declining a Donor

- Inadequate kidney function to donate
- Diabetes or impaired glucose tolerance
- Obesity
- Cancer
- Active substance misuse
- Uncontrolled blood pressure
- Unsuitable anatomy (too many arteries or veins)
- Psychosocial issues, coercion, inability to give informed consent



#### Living Donor Assessment Process





## DONOR STATS: ENROLLMENT TO DONATION (SPH EXPERIENCE OVER 3 YEARS)





### Kidney Paired Donation (KPD) Program

- Kidneys are shared Canada-wide
- Considered if a donor approved but is not a suitable match for their intended recipient
- Also suitable for anonymous donors
  - Not linked to any recipient



# Some facts about kidney paired donation

- Entering the paired donation cycle does not guarantee a match
- The donor
  - Must be approved by a centre in Canada
  - May have to travel
  - Remains anonymous to their matched pair



## **Out of Country Donors**

- Must be known to the recipient
- Must be blood type compatible
- Must have access to health care
- Visitor's Visa may be required (but not granted)
- Donor testing repeated once in Canada (covered by MSP)
- Still may be found unsuitable



## **The Donor Surgery**

Two types of donor incision:

• 1. Laparoscopic (minimally invasive surgery)

2. Open nephrectomy





#### **Donor's Surgical Risks**

- Living donation is major surgery
  - Length of hospital stay typically 3-4 days
- Complication rates are low
- Most common concerns after surgery:
  - Incision pain for 1-2 weeks
  - Nausea for 24-48 hours
  - Constipation for 1-2 weeks
- Risk of a serious complication is 1 2%
- The risk of dying as a result of the operation is 0.03%


#### What to Expect Long term

- Life expectancy not reduced
- Long term kidney function about 70% of pre-donation
- Risk of kidney failure later in life very low (<1%)
- Pregnancy considerations
  - Closer follow-up recommended during pregnancy
- Long term risk of proteinuria, higher blood pressure



#### Donor Long-Term Follow Up

- Life long follow up required
- Annual medical exams with family physician
  - Lab work, Blood Pressure
  - Results are copied to Transplant centre and reviewed
- Transplant team consults as needed



## SOCIAL WORKER ROLES



#### **Recipient Social worker roles**

#### Home Team Social Worker (KCC/Dialysis)

- Ongoing support before transplant
- Assistance with donor outreach
- Works with you and the transplant team to plan for transplant
- Transplant Social Worker
  - Conducts transplant assessment
  - Provides counselling and emotional support
  - Additional donor outreach support and strategies
  - Assists with transplant planning (accommodation, support plan, additional resources)
  - Support during surgery and recovery while in Vancouver



#### What is Donor Out reach?

- Most people benefit from a living donor transplant
- It can be hard to talk about living donation and your need for a transplant
- It is important you are comfortable with doing outreach
- Your home and transplant teams know what has helped others and can offer you information, tools and support
- Support can increase the effectiveness of your outreach efforts



#### **Information For Recipients**

- Donors often offer to donate once they understand the need
- Donors are equally concerned about their relationship with you
- Donation is not the right emotional fit for everyone
- Donors are never obligated to donate and no pressure is placed on them
- Donors obligations/responsibilities are considered and planned for



#### After Doing Outreach

- Finding a donor can take a while
- Receive ongoing emotional support
- Trust the process and talk to your home and transplant teams as it unfolds
- Focus on the positives of your efforts, outreach is a way to be active in your medical treatment plan
- Provide regular updates to your friends and family



#### **Additional Recipient Support**

- Kidney Foundation Peer Connect Program (for Recipients)
- Home or Transplant SW can help you connect with a recipient
- For more information: The Kidney Foundation <u>www.kidney.ca/bc</u> or 1-800-567-8112



#### **Donor Social Worker**

- Meets with donors during assessment for donation
- Assists donor to explore whether donation is the right decision
- Provides supportive counselling around donation and any related concerns
- Assists with practical tasks and planning for donation
- Provides support and assistance through surgery and recovery



#### **Donor's Perspective**

- See donation as a gift
- Often report it was an "automatic" decision
- Don't want attention or any "fuss" about donation
- Report it was a rewarding experience for them
- Lead normal, healthy life with one kidney



### Donor Social Work Role After Donation

- Provides ongoing support during recovery
- Liaises with medical team regarding any concerns
- Assists with practical concerns related to recovery
- Provides counselling support regarding recovery and expectations



### DONOR PROGRAMS

- Living Organ Donor Expense Reimbursement Program (LODERP)
- Assists donors with some out of pocket expenses

#### Living Donor Mentorship Program

- Trained volunteer kidney donors can connect with people considering donation
- Matches kidney donors and potential donors with similar backgrounds, lifestyles
- For more information: The Kidney Foundation <u>www.kidney.ca/bc</u> or 1-800-567-8112



# LIVING KIDNEY DONOR EXPERIENCE



# QUESTIONS & ANSWERS FOR THE DONOR TEAM



#### **Consider your transplant Options**

- Learn about Transplant and Living Donation
- Bring family & friends to education sessions and appointments
- Get support from your Home and Transplant Teams
  - Use Donor outreach tools and sample letters
- Living Donor Transplant gives the best results and is the only way to get a transplant before starting dialysis



### **INFORMATION & RESOURCES**

**BC Provincial Renal Agency:** www.bcrenalagency.ca **BC Transplant**: www.transplant.bc.ca Kidney Foundation: www.kidney.ca/bc The Living Donor The **Kidney Transplant** Finding a Donor **Kidney Transplant** Process Process Getting the Word Out: A step-by-step guide for A step-by-step guide for A step-by-step guide for reaching out to potential donors 

#### More Connections....



- Peer Support Kidney Connect Program (Kidney Foundation):
  - You will be paired with a trained volunteer who has experienced a transplant or been a living donor. Go to <u>https://kidney.ca/peer-support</u>
  - Program is telephone-based
  - Call 1-866-390-PEER (7337) to request a peer support volunteer
- BC Renal website (transplant section):
  - <u>www.bcrenalagency.ca/health-info/managing-my-care/transplant</u>
- BC Transplant website (living donation section):
  - www.transplant.bc.ca/health-info/organ-donation/living-donation
- Kidney Foundation website: <a href="https://kidney.ca">https://kidney.ca</a>



**Kidney Transplant & Finding a Living Donor** 



Thank you for taking the time to complete the feedback form (will be send to you after the session)

