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Kidney/Pancreas Transplantation Education

Inova Transplant Center

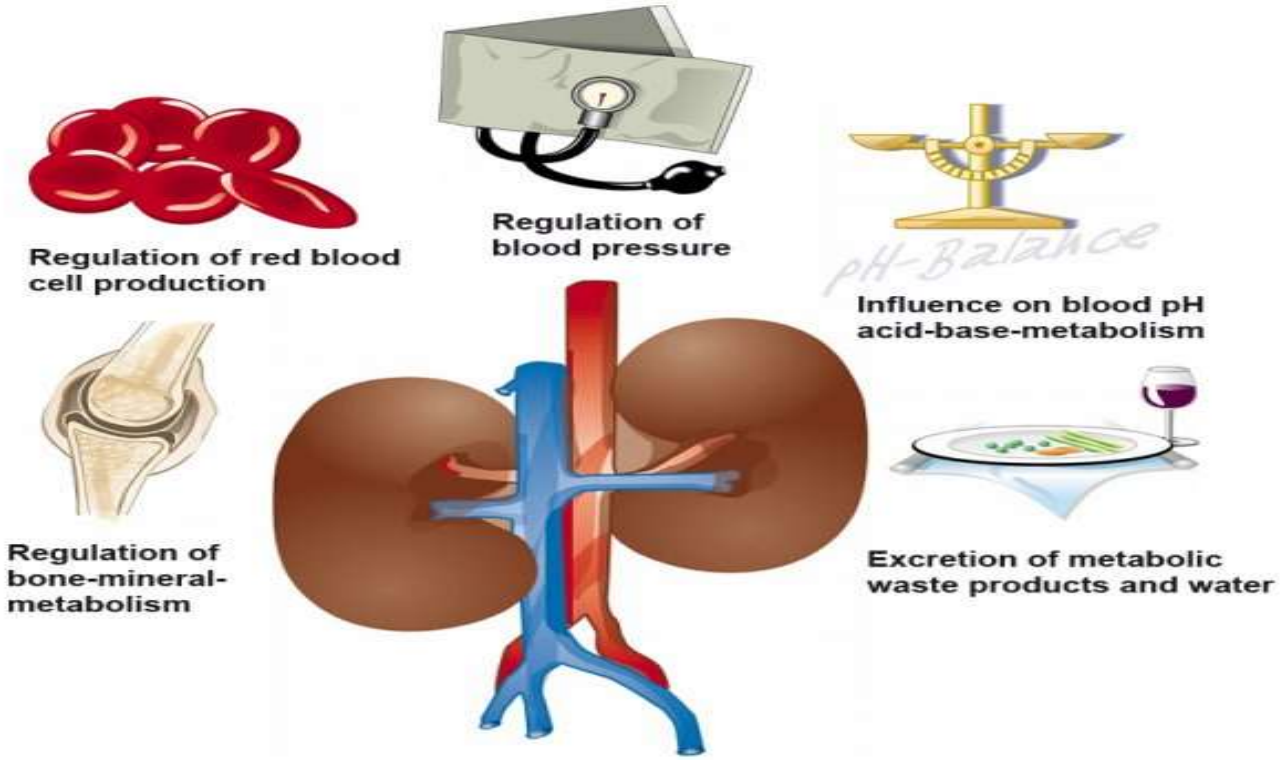
Kidney Transplant Coordinators

Grace Capuno, RN, BSN
Nancy Atouani, RN, MSN

Transplantation

- Transplantation is a proven method to treat kidney failure - not a cure!
- It is a major surgery with potential complications.
- It is a lifelong commitment to care for a transplanted organ.
- Education materials provide information to help make an informed decision about whether or not to proceed with transplantation.

Kidney Failure



Treatment of kidney failure includes

- Dialysis
  - Hemodialysis
  - Peritoneal dialysis
- Transplantation

Comparison: Dialysis vs. Transplant

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Dialysis	Functioning Transplant
Dietary Restrictions	More liberal diet, no phosphorus restriction
Fluid Restriction	No fluid restriction
Fatigue, lack of energy	Increased energy
Anemia, blood chemistry imbalance	Improved blood test results
Sexual dysfunction/difficulty getting pregnant	Improved sexual function
Decreased quality of life	Improved quality of life
Increased death rates	Decreased death rates

Transplant Process

- **Pre-Transplant Education**
- **Initial Evaluation**
- **Listing Process**
- **Living Donor Evaluation** **(if applicable)**
- **Pre-Transplant Care**
- **Transplantation**
- **Post-Transplant Care**

Sources of Kidneys for Transplant

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- Living donors

  - Paired exchange

- Deceased donors

  - Direct donation

Living Donors

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- Age 18 or over
- Good physical health – no uncontrolled high blood pressure, diabetes, heart disease, recent cancer, obesity (BMI >35).
- Stable emotional health.

Blood relatives

- brothers/sisters
- parents
- children
- cousins
- aunts/uncles

Unrelated

- spouses
- close friends
- co-workers
- church members
- in-laws

Living Donor Coordinator Kirsten Greeley, RN 703-776-8053.

Living Donation Expenses

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- **QUESTION:** Can I help my potential living donor with donation-related expenses? I thought it was illegal to pay someone for an organ?

- **ANSWER:** Yes, you can help your potential living donor with donation-related expenses including meals, travel, lodging, and lost wages. This includes evaluation expenses, even if your donor is ruled out.

However, you cannot simply pay your potential living donor for their kidney.
See below for more information.

- In 1984 Congress passed the National Organ Transplant Act (NOTA), which prohibits the sale of human organs. However, the payment of "the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ" is expressly permitted by section 301 of the NOTA.

*Please reference the Living Donation Expenses handout in your patient folder for more information on financial resources.

TALKing about living donation

Talking to people about living donation can be difficult…

This video and booklet will help you:

- ✓ Learn how to talk about kidney disease
- ✓ Understand the living donation process
- ✓ Navigate conversations with potential donors
- ✓ Know what to expect after transplant

Visit the website below to access the TALK video and booklet. Please watch before your evaluation appointment and write down any and all questions to discuss with the transplant social worker.

http://ckddecisions.org/talk-materials/#

Deceased Donors

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- The donor is a person who has been declared dead (DBD-donation after brain death, DCD-donation after cardiac death) and whose wishes were to donate their organs.
- Medical history reviewed with transplant surgeon.
- Testing done to check for general health status, organ function, and infectious diseases.

"Increased Risk" Donors

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An **"Increased Risk"** donor is defined as a person who meets 1 or more of the 11 criteria ***in the past 12 months.***

People who have…

Had sex in exchange for money or drugs.

MSM-men who have sex with men

Injected drugs by IV, IM, SQ route for nonmedical reasons

Been in lockup, jail, prison, or a juvenile correctional facility for more than 72 hours

Newly diagnosed with or have been treated for syphilis, gonorrhea, Chlamydia, or genital ulcers.

Been on hemodialysis (increased risk for HCV only)

People who have had sex with a person…

Who had sex in exchange for money or drugs.

(Women) who have had sex with a man with a history of MSM behavior.

Who Injected drugs by IV, IM, SQ route for nonmedical reasons

Known or suspected to have HIV, HBV, or HCV infection.

A child who has…

(≤ 18 months of age) Been born to a mother know to be infected with or at increased risk for HIV, HBV, or HCV infections.

Been breastfed and the mother is known to be infected with, or at increased risk for HIV infection.

"Increased Risk" Donor Information

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- **1 in 5** donors are deemed to be "Increased Risk."
- Increased risk does not mean that the organ is of lower quality.
- Donors tend to have more characteristics associated with favorable graft function such as younger age and better serum creatinine.
- The risk of declining an organ may be greater than the risk of a donor-derived viral infection.
- **NAT** testing is utilized to identify early infections in donors.
- The risk of virus transmission from donor to recipient becomes extremely small if a risk behavior occurred more than three weeks prior to NAT testing.
- Even under the highest risk behavior, the transmission risk of HIV, Hepatitis B or Hepatitis C from a NAT negative donor is <1%.
- Treatments for HIV, HBV and particularly HCV have improved.

The risk of getting Hepatitis C on dialysis is 0.34% per year or 1 in 3,000

"Increased Risk" Organs

- **NAT testing:**
  - **N**ucleic **A**cid **T**est (or NAT) is a test used to detect a virus or bacteria in blood, tissue or body fluid.
  - This test was developed to shorten the window period (time between infection and when a person shows up as positive).

- **Benefits:**
  - Detects low level of virus.
  - Allows detection of infection in the incubation period.
  - Highly sensitive.

Programs at Inova Fairfax Hospital

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- **Kidney**
- **Kidney/Pancreas**
- **Pancreas after Kidney**

The Transplant Center Team:
A Patient Centered Multidisciplinary Approach

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- **Transplant surgeons**
- **Nephrologist**
- **Transplant coordinators**
- **Nurses**
- **Social workers**
- **Psychiatrist**
- **Physician assistants**
- **Cardiologist**
- **Dietician**
- **Diabetic specialist**
- **Financial coordinators**
- **Research coordinator**
- **OPO**
- **<u>Most important</u> - You**

Transplant Support Person

- Research shows that recipients with good social support have better outcomes

- Support person must be available throughout transplant process:
  - During evaluation
  - During transplant surgery
  - After transplant

- When selecting a support person, consider the following:
  - Must be at least 18
  - **Must be available to attend the on-site evaluation with you**
  - Must be available to assist you at the time of transplant
  - Must have no active substance abuse issues
  - Must be mentally and emotionally stable

The Social Worker must be able to discuss your post-transplant care plan with your support person. If they do not attend evaluation, this may prolong the listing process.

Transplant Physician Team

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Transplant Surgeons

- **Johann Jonsson, M.D., F.A.C.S.**

- **James Piper, M.D.**

- **Eric Siskind, M.D.**

Transplant Nephrologist

- **Ravinder Wali, M.D.**

Evaluation

Evaluation Process

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1. Financial information and medical records reviewed
2. Pre-Transplant education
3. Insurance authorization for evaluation
4. Team Evaluation
5. Medical testing & consultations
6. Transplant surgeon consult
7. Collaborative Practice Meeting case presentation
8. Insurance Authorization for transplant surgery

You are expected to complete the evaluation process in 90 days

If you do not complete the evaluation in 90 days your file may be "closed"

Communicate with transplant team if you are experiencing delays in the evaluation process

Tests for Kidney Transplant Evaluation

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- Chest X-ray
- Abdominal ultrasound
- EKG
- Blood tests
- Tuberculosis testing
- CT scan
- Additional tests (if needed)
  - Cardiac stress test
  - Iliac vessels ultrasound
  - **Colonoscopy (50 years or older)

- <u>For Females</u>
  - **Mammogram (40 years & older)
  - **Pap smear/GYN exam
- <u>For Males</u>
  - PSA

** Cancer screening required if patient has immediate family members with history of cancer (parents or siblings).

Financial Considerations

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- Assigned a financial coordinator to review insurance policies and plans.
- Patients with Medicare are required to have a secondary insurance that is **NOT** paid for by their dialysis unit.
- Medicare entitlement based on ESRD only will end at 3 years after transplant.
- Financial coordinator & social worker can help locate resources for financial assistance if needed.
- Cost of medications after transplant would be over $3000 “out of pocket” per month without proper insurance coverage.
- In order to qualify for reimbursement for medications **the transplant surgery must be performed at a Medicare approved facility.**

Kidney Transplant Candidacy

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Indications

- Creatinine clearance or GFR of < or = to 20.
- ESRD with chronic hemodialysis or peritoneal dialysis.

Contraindications

- Recent cancer (excluding skin cancer)
- Poor compliance
- Active, untreated infections
- Severe organ diseases
- Psycho-social or psychiatric issues that impair ability to care for self
- Current substance abuse
- Medical conditions without potential for rehabilitation
- Obesity-determined by **B**ody **M**ass **I**ndex (BMI) and surgeon assessment
- Inadequate insurance coverage for transplant

Pancreas Transplant Candidacy

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Indications

- Long standing type I diabetes
- C-peptide of <0.5

Contraindications

- Age > 55 years old
- Chronic, recurrent gangrene infection
- Severe heart disease
- Major amputations
- Blindness without sufficient alternative support system
- Severe nerve damage
- Obesity (BMI > 32)
- *Same general contraindications as kidney transplant

Waitlist

Listing Notification

- Your transplant coordinator will call you when you are placed on the waiting list – (you must have completed **all** diagnostic testing, been cleared by the transplant surgeon and been accepted by hospital committee).

- At this time, you must tell your coordinator how you can be reached (i.e. cell phone, home phone, work phone) – the Transplant Center must be able to reach you at all times!

- An official letter will be sent to you, your nephrologist, and dialysis center when you are listed.

Waiting for a Transplant

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- Once listed you will be assigned a Waitlist Coordinator.
- You are required to be reevaluated annually by the team while on the waitlist to ensure you are ready to receive a transplant*. At this visit:
  - Testing will be updated
  - Health updates will be discussed
  - Finances will be reviewed/checked

*If you decline to be reevaluated, you will be made inactive on the waitlist.

Communication with Transplant Center

- **Notify *us* with any changes to:**
  - Phone numbers/address
  - HD unit
  - Physician
  - BEFORE you change your health insurance
  - Major illness or hospitalizations

- **As a Medicare requirement, we will notify *you* if:**
  - Inactivity of program
    - Duration
  - Program closure
    - Assist patient to transition to another center
    - Transfer of wait time

Monthly Phone Calls – **XYN Management**

- Check on any changes you may have with demographic information and/or health changes.
- Reports emailed to the Transplant Team for follow up and updating of your records.

PRA-Panel Reactive Antibody

- Lab test to determine exposure to foreign tissues (pregnancies, blood transfusions, infections and/or previous transplant).
- Testing positive means that a person is “sensitized.”
- Exposure percentage can range from 0% to 99%, the higher the percentage the more “sensitized.”
- Being “sensitized” may make it more difficult to find a compatible match.

PRA-Continued

- Drawn monthly or quarterly.
- Blood samples used at a moments notice when a donor becomes available for you!
- If PRA samples are not current, you may be passed over for an organ offer.
- Sent from dialysis unit or via FedEx by patient to Johns Hopkins Lab
- ***It is your responsibility***, not the responsibility of your dialysis center to make sure that your samples are sent to Johns Hopkins.

Health Maintenance

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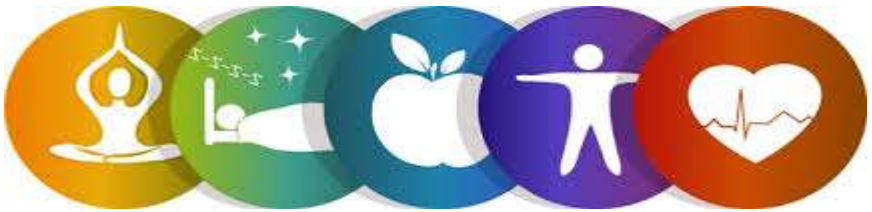
- **Important to maintain health including:**
  - Regular visits to Health Care Provider
  - Regular visits to your Dentist
  - Eat healthy foods
  - Control your weight
  - Exercise regularly
  - Get all your immunizations
  - Complete cancer screening



Recipient/Donor Matching

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- Blood type
- HLA tissue matching
- Crossmatch

Blood Type Compatibility

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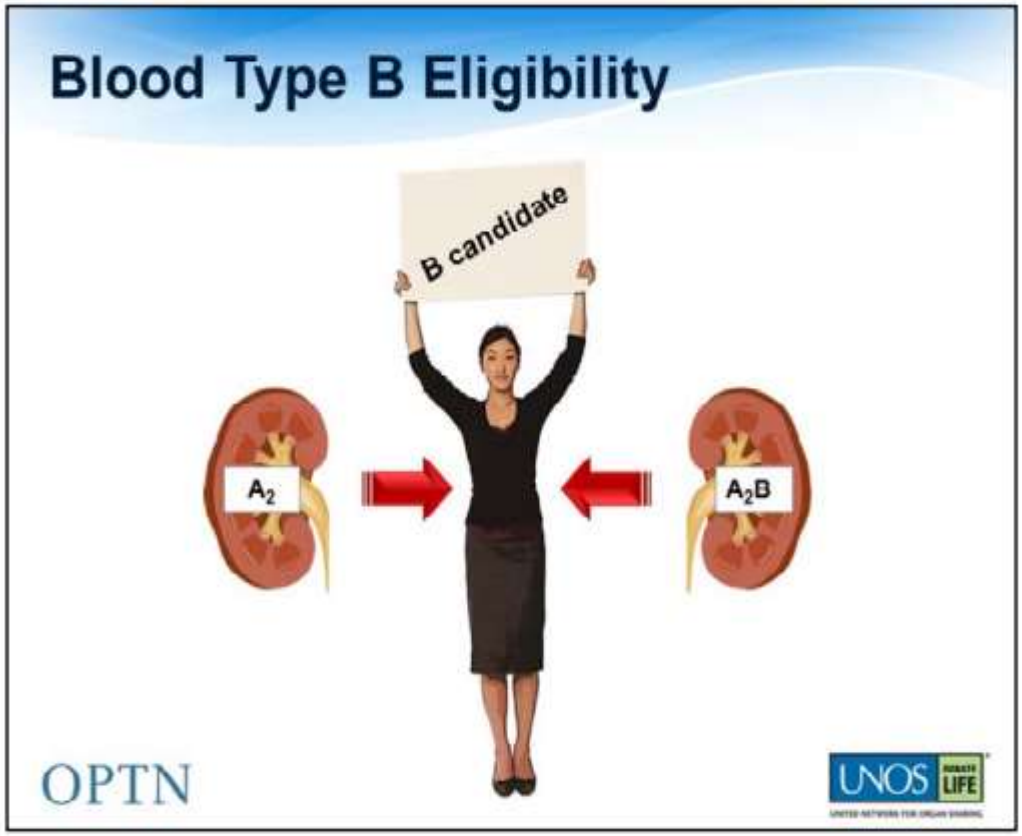
Recipient	Donor
O	O
A	A,O
B	B,O, A_2
AB	A, B, AB, O

* Rh Factor (+/-) does not matter for Kidney Transplant

Blood Type B



Blood type B candidates have less access to deceased donor kidneys, resulting in lower transplant rates.

However, based on titer levels…

Low titer level=*Eligible for B or A2/A2B kidneys.*

High titer level=*Eligible for B Kidney only.*

To receive an A2-B kidney you will need to sign a consent form.

HLA Tissue Typing

- **HLA**-*Protein found on most cells of the body and used to match with a donor for organ transplant.*
- Tissue typing is blood test is to determine the tissue type of the patient and the potential donor to see how well they match.
- Each person's tissues (except identical twins) are usually different from everyone else's.

A better match will lead to a more successful transplant over a longer period of time.

Crossmatch

- Recipient & donor blood cells are mixed together.
- Checks for a reaction of the recipient cells against the donor cells.

  Positive reaction – Incompatible/no transplant

  Negative reaction – Compatible/ok to transplant

Kidney Allocation

Organ Allocation System

- **United Network for Organ Sharing (UNOS)**
  - Non-profit organization that manages the nation's organ transplant system
  - All transplant centers in the US must abide by the regulations and policies mandated by UNOS

- **Washington Regional Transplant Community (WRTC)**
  - Local **O**rgan **P**rocurement **O**rganization (OPO)
  - Works with all deceased donors and their families

Local, Regional and Nationwide Organ Offers

- **Local**
  - This is the area served by the local organ procurement organization (OPO) where the donation occurs.
- **Regional**
  - If there are not suitable local matches, organs are offered to transplant hospitals in a wider area.
- **Nationwide**
  - If there are no matches in the local area or region, organs are offered to anyone in the United States who is a potential match.

Multiple Listing

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- **Multiple Listing**
  - Involves registering at two or more transplant hospitals.
  - Some studies suggest that multiple listing can shorten the average wait time by several months (but this is not guaranteed).
  - You probably would not benefit from listing at multiple hospitals in the same local allocation area. This is because priority is calculated among all hospitals within the local donation area, not for each hospital.
  - You should always check with your insurance first to make sure that additional evaluations are covered.

Regional Kidney and Kidney/Pancreas Transplant Programs

University of Virginia Health Science Center
Charlottesville, VA
- (434) 924-0211

Sentara Norfolk General Hospital
Norfolk, VA
- (757) 388-3000

Henrico Doctor's Hospital
Richmond, VA
- (804) 289-4500

Medical College of Virginia Health System
Richmond, VA
- (804) 828-9000

Johns Hopkins Hospital
Baltimore, MD
- (410) 955-5000

University of Maryland Medical System
Baltimore, MD
- (410) 328-6363

WRTC

Walter Reed National Military Medical Center
Bethesda, MD
- (301) 295-4330

Children's National Medical Center
Washington, D.C.
- (202) 476-5000

Medstar Georgetown University Medical Center
Washington, D.C.
- (202) 444-3700

George Washington University Hospital
Washington, D.C.
- **(**202) 715-4000

***National Transplant Center List can be found at www.UNOS.org**

Kidney Allocation System

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- New kidney allocation system introduced by UNOS in December of 2014.

Allocation System Goals

- Match a kidney that is expected to function the longest with people who are expected to need a kidney for the longest time.
- Improve possibility of transplant with people who are hard to match based on blood type and immune sensitivity.
- Improve fairness with wait time calculations.

Kidney Allocation System

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- Based on a “points system”
- No urgency status listing
- Average wait time for a deceased donor is 4-8 years
- Your status on the list changes with ***every*** organ offer

Kidney Allocation System

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- **Factors used to calculate KDPI Score**

  - Age
  - Height and weight
  - Ethnicity
  - Stroke as cause of death
  - History of high blood pressure
  - History of diabetes
  - Exposure to the hepatitis C virus
  - Serum creatinine (a measure of kidney function)
  - Whether the donor died due to loss of heart function or loss of brain function

Kidney Allocation System

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- **Kidney classification**
  - Every kidney offered will have a **K**idney **D**onor **P**rofile **I**ndex (KDPI) score
    - Score ranges from 0 to 100 percent
    - The score is associated with how long the kidney is likely to function when compared to other kidneys

KDPI 20%

Functions better than 80% of available kidneys

0% KDPI

50%

100% KDPI

KDPI 60%

Functions better than 40% of available kidneys

0% KDPI

50%

100% KDPI

Donors with KDPI Score 86 to 100

- Deceased donors with certain medical conditions:
  - Age > or = 50 with hypertension
  - Creatinine > 1.5 or cause of death related to stroke
  - Age > or = 60 that are otherwise healthy or with any of the above conditions)

- Patients must sign a consent form to be considered for donor transplantation – this will be reviewed with patients individually at the transplant coordinator visit.

- Tissue biopsy may be performed to ensure a healthy organ before the kidney is accepted and used for transplantation.

- Patients who accept these kidneys may be transplanted sooner, but the organs may not last as long.

Kidney Allocation System

- Each transplant candidate will have an **E**stimated **P**ost **T**ransplant **S**urvival (EPTS) score calculated
  - Score is associated with how long a candidate will need a functioning kidney transplant when compared to other candidates

EPTS=20%

- Needs a kidney 80% longer

EPTS=60%

- Needs a kidney 40% longer

Kidney Allocation System

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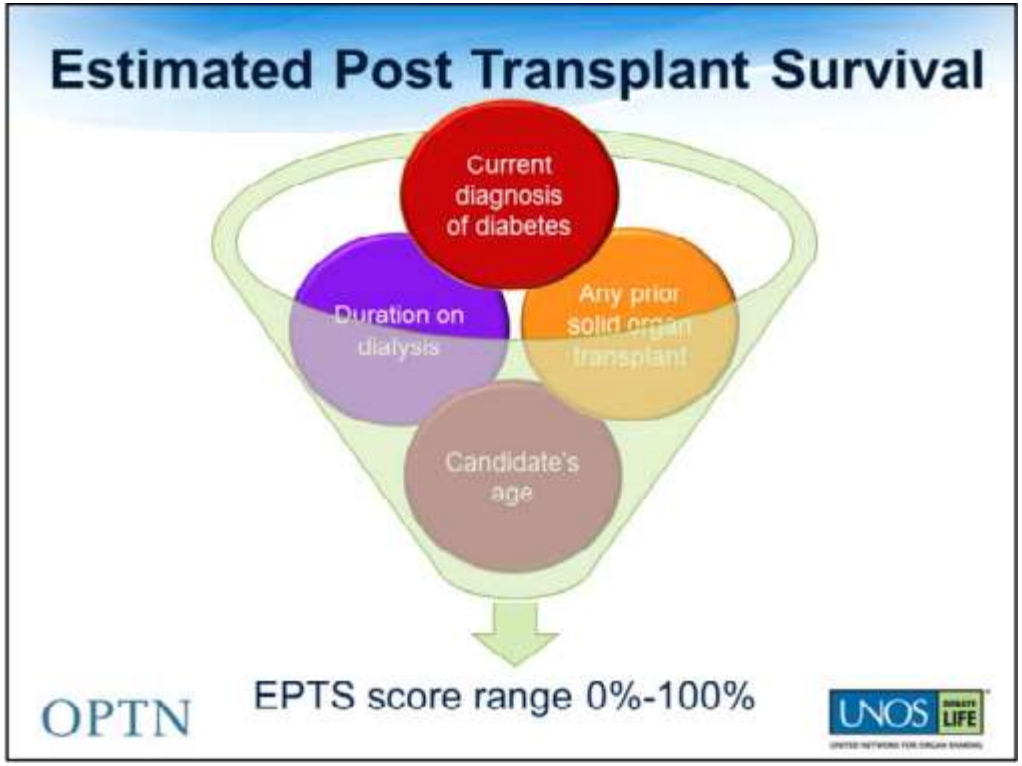
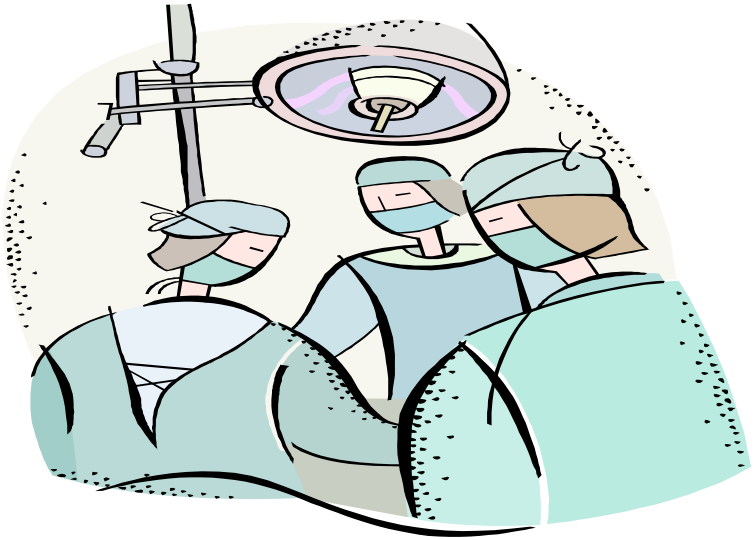
- **Factors used to Calculate EPTS Score**



Transplant



Organ Offer

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1. WRTC notifies the transplant coordinator & surgeon about donor medical information.

2. Surgeon and transplant coordinator review possible matching candidates.

3. OR time is scheduled for the donor.

4. Decision is made by the surgeon to accept the organ based on anatomy and visual inspection.

5. Possible recipients are notified of potential organ and blood cross matching is done.

6. 2 patients will be ‘primary’ and others will be ‘back ups’ for the kidney (s).

When You Are Called for Your Transplant

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- **Stop eating and drinking as instructed by the on call transplant coordinator.**

- **Tell your coordinator**
  - How long it will take you to reach the hospital & have a transportation plan in advance.
  - When you last had dialysis.
  - Any recent blood transfusion.
  - Any recent illness or infection.

- **Bring only necessities to the hospital**
  - Insurance cards, photo ID, & list of medications
  - Leave valuables at home.

- **If tissue crossmatch is negative and kidney offer is accepted:**
  - Patient is admitted to INOVA Fairfax Hospital.
  - Blood work, EKG, and x-rays are completed.
  - Patient will be admitted to Short Stay Unit where they will be prepared for the OR.

Kidney Transplant Surgery

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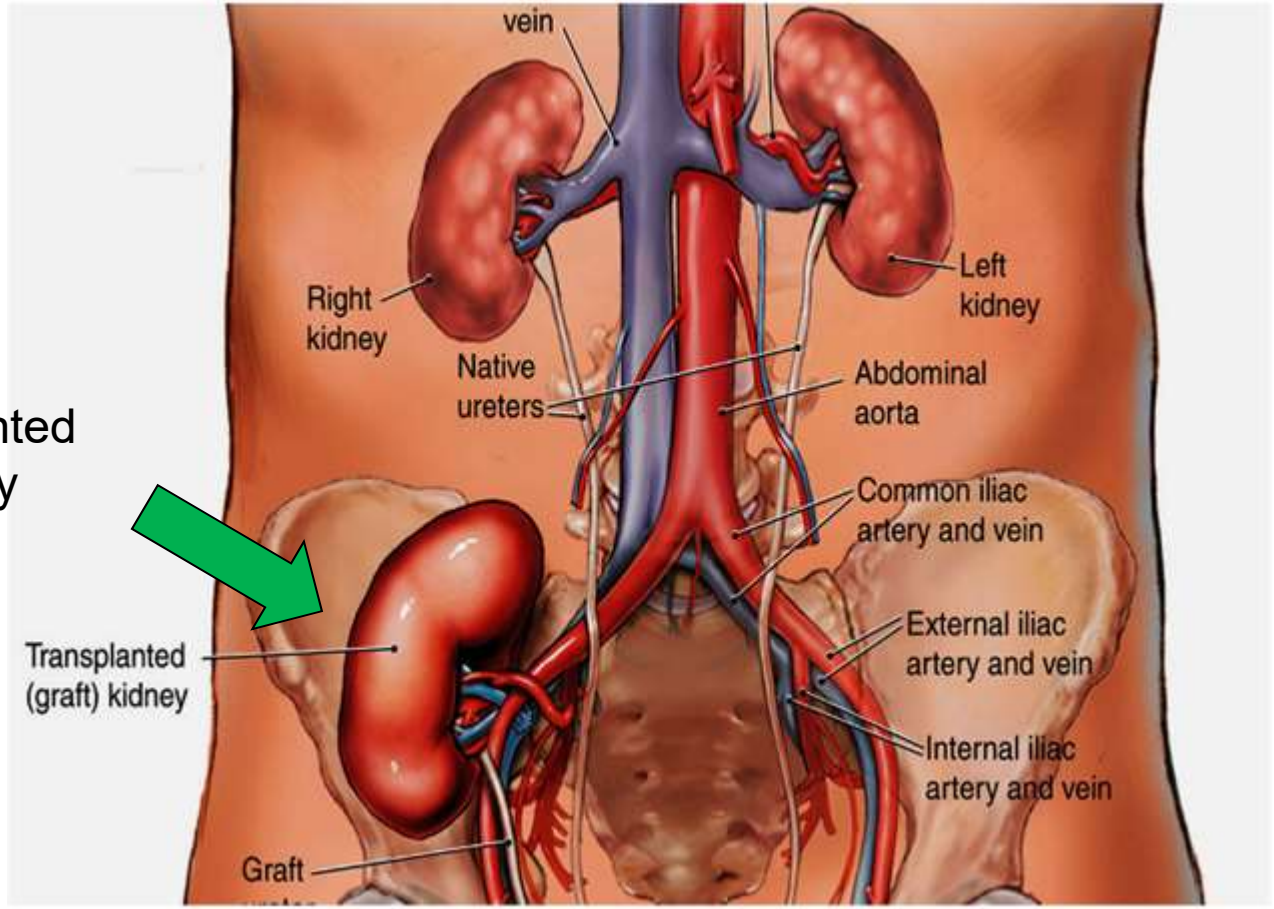
- Done under general anesthesia.
- Operation takes 3 - 4 hours.
- Usually requires no blood products.
- Transplanted kidney placed in the lower abdomen.
- Donor blood vessels and ureter are connected to recipient's blood vessels and bladder.
- Native (old) kidneys are not removed.
- 3-5 total days in hospital.

Kidney Transplant

Right

Left

Transplanted Kidney



Potential Complications

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Surgical (Intra-Op)

- Technical
- Bleeding
- Infection
- Blood clots
- Risk of anesthesia

After Transplant (Post-Op)

- Primary non-function
  - Kidney never starts working
- Delayed graft function
  - Kidney is slow to start working
- Rejection
- Infection
- Anti-rejection medication complications
  - High blood pressure
  - Diabetes
  - High cholesterol
  - Lymphoma
  - Skin cancer

Pancreas Transplant

- For Type I, non-insulin producing diabetics only.
- **Types:**
  - Simultaneous deceased donor kidney/pancreas transplant.
  - Pancreas after previous kidney transplant.
- Evaluation same as kidney transplant with additional blood testing and may need additional cardiac testing or consultation.
- 1-3 year waiting time.

Pancreas Transplant

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- **Advantages:**
  - No longer require insulin.
  - A more liberal diet.
  - Advancement of diabetic complications may decrease or stabilize.

- **Disadvantages:**
  - Limited donor source.
  - Higher incidence of complications than kidney transplant (bleeding, infection, thrombosis).
  - Longer surgery and hospital stay.

Pancreas Transplant Surgery

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- Done under general anesthesia.
- Native (old) pancreas is not removed.
- Midline abdominal incision.
- Donor and recipient blood vessels are attached.
- Portion of donor intestine is attached to recipient's intestine to provide drainage of digestive enzymes.
- Operation takes 4-6 hours.
- Hospital stay 5-7 days.

Pancreas Transplant

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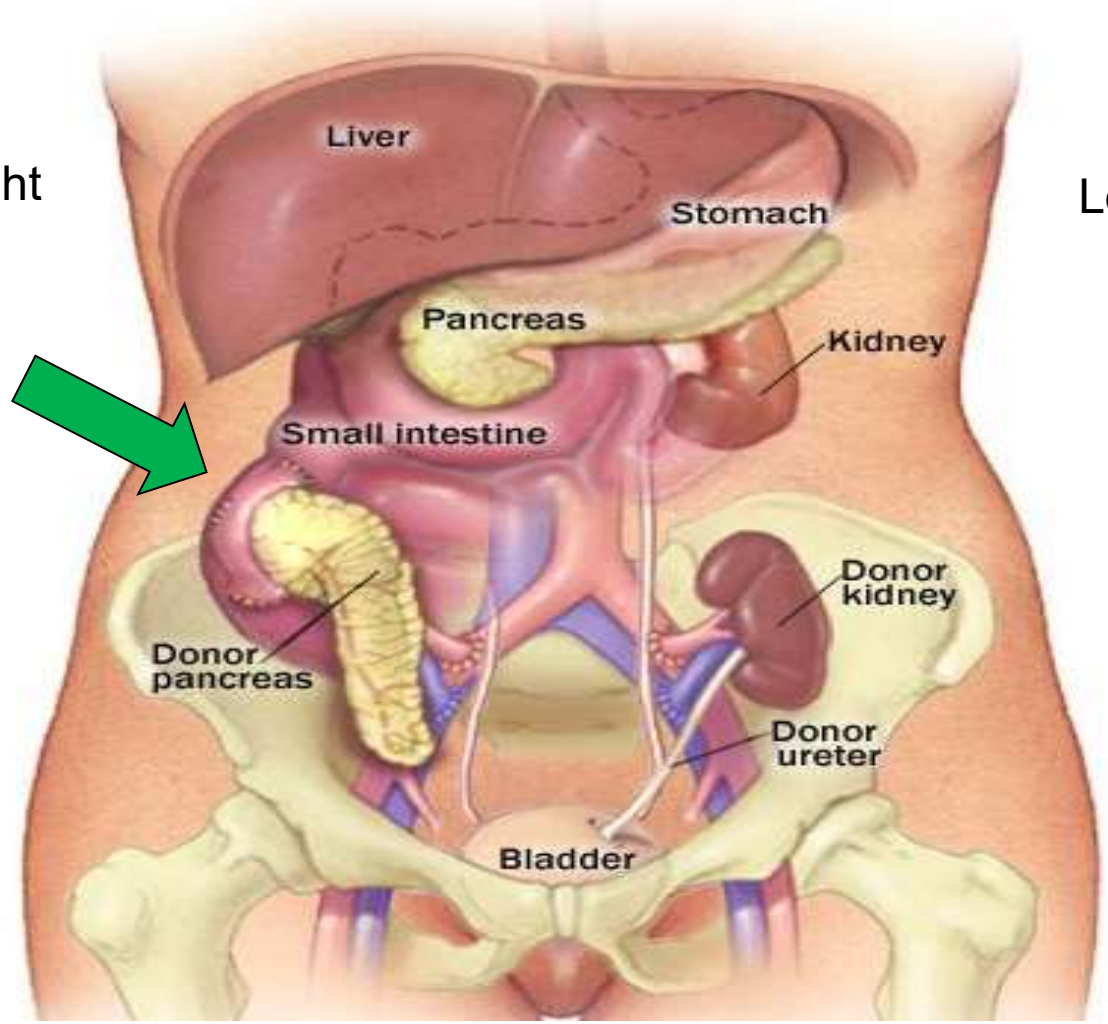
Right

Left

Transplanted Pancreas



Kidney Pancreas Transplant Surgery

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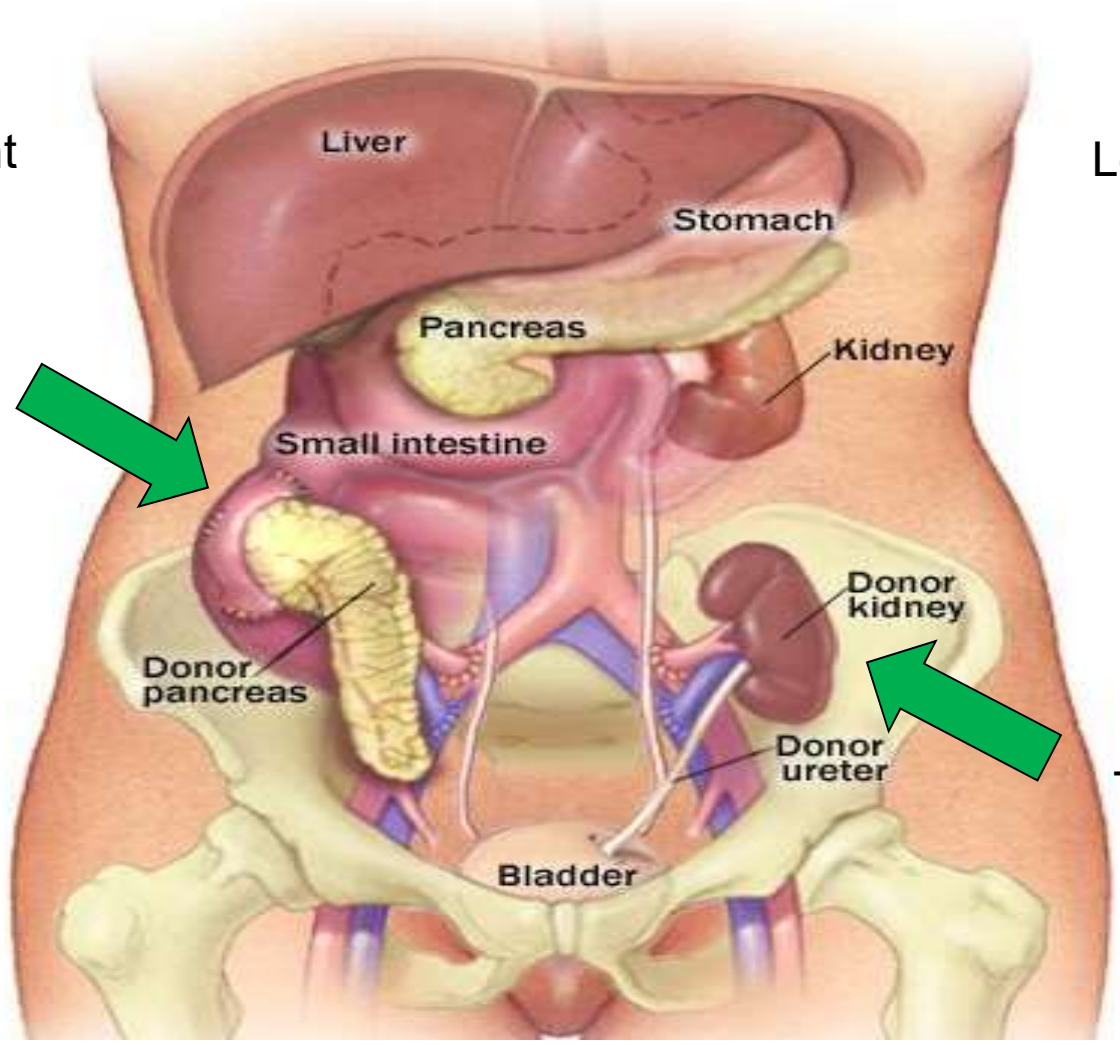
Right

Left

Transplanted Pancreas

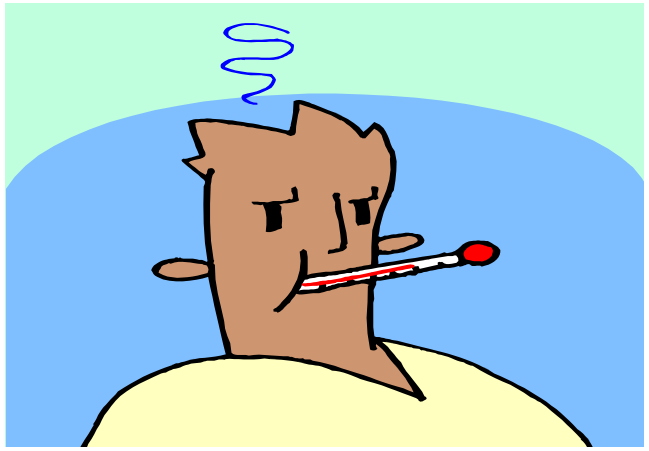


Transplanted Kidney

Post-Transplant

YOU WILL BE ASKED TO MONITOR AND RECORD THE FOLLOWING:

- Temperature
- Blood pressure
- Weight
- Oral intake
- Urine output
- Blood sugar (diabetics only)



Remember

- No heavy lifting (>10 lbs.)
- No driving for 4-6 weeks

Follow Up Care

- ***Visits at the transplant center for the first 3 months after surgery are more frequent to ensure you are healing well and your organ is working well.***
- Frequency of visits decrease when appropriate.
- Blood work done at each visit to monitor immunosuppressive drug levels and check for rejection.
- Kidney biopsy performed: 90days, then annually for first 3 years to monitor for rejection and/or recurrent disease in the kidney.
- **Post-transplant education**
  - Medications
  - Signs of rejection and infection
  - When to call the transplant coordinator

Medications Post-Transplant

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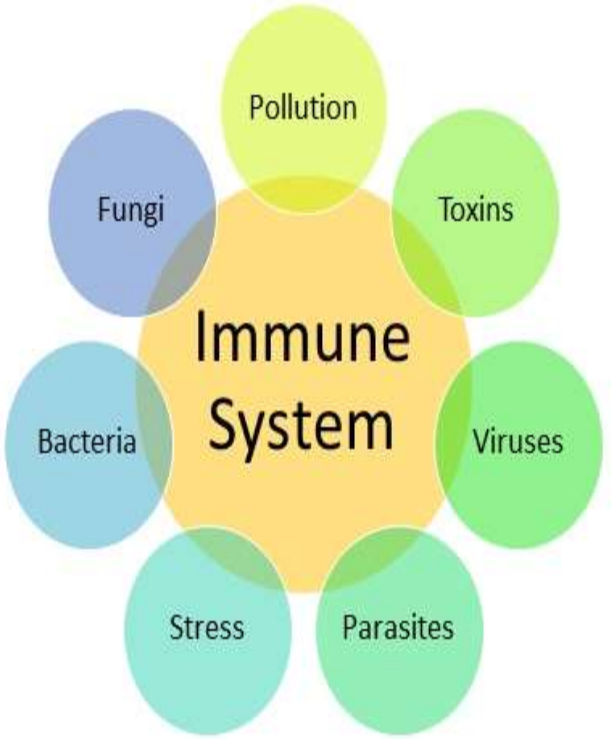
Medication	Reason
Prograf	To Prevent Rejection For Lifetime (Not all medications are taken but a combination of 2-3)
Cellcept	
Prednisone (not in all patients)	
Rapamune	
Belatacept	
IV steroids	To Treat Rejection (if needed)
Thymoglobulin	
Valcyte	To Prevent Infection (For short/varied amounts of time)
Bactrim	
Flagyl	

The Immune System

- Cells in the body that work to find and destroy foreign substances such as bacteria, viruses, **and transplanted organs.**
- Body's natural defense mechanism to protect us.
- Immunosuppressive transplant medications lower or weaken the body' immune system response so that the transplanted organ will not be rejected.
- These medications must be taken for lifetime to prevent organ transplant rejection



Rejection

- Fever
- Fatigue/weakness
- Tenderness of kidney
- Decrease urine output
- Increase weight gain
- Swelling of ankles/hands
- Increased blood sugar in pancreas transplant

Infection

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- Fever > 100 degrees F
- Flu-like symptoms:
  chills, aches, fatigue, headaches,
  dizziness, nausea, and vomiting
- Productive cough and/or shortness of breath
- Nasal congestion with green or yellow drainage
- Sore throat
- Diarrhea
- Pain and burning with urination, or feeling constant urge to urinate
- Any wound that is red, swollen, has drainage and/or pain
- Mouth sores or thrush
- Rashes or skin lesions

Life Changes After Transplant

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Join the future of health.

- No further need for dialysis
- Return to work
- No fluid restriction
- More liberal diet
- Travel
- Improved fertility for women
- Overall improved quality of life

But Remember…

- Good compliance mandatory for successful transplant
- Immunosuppression for life

Transplant Related Web Sites

www.inova.org

www.unos.org

www.wrtc.org

www.niddk.gov

www.srtr.org

http://ckddecisions.org/talk-materials/