



UC DAVIS TRANSPLANT CENTER
(916) 734-2111 or (800) 821-9912

UC DAVIS MEDICAL CENTER
2315 STOCKTON BOULEVARD
SACRAMENTO, CALIFORNIA 95817

Dear Prospective Donor,

Considering organ donation is an extraordinary act of kindness. The decision to actually become a living donor should be based on a clear understanding of the benefits as well as the risks. The goal of this material is to ensure you are informed and confident about the entire process.

There is a lot of important information in this material, some of which you may feel is not needed at this time. We encourage you to learn all that you can until you are absolutely comfortable with your decision.

When you decide to proceed, you will be working with a team of dedicated, exceptionally qualified professionals who are committed to your well being. The UC Davis Transplant Team proudly contributes to the 15,000 kidney transplant performed each year in the United States – of which more than 40 percent come from living donors.

We look forward to working with you and your loved one toward a successful living donor transplant. Please call the transplant center at 916-734-2111 or 1-800-821-9912 if we can be of any assistance.

Sincerely,

A handwritten signature in black ink that reads "Richard V. Perez".

Richard Perez, MD
Transplant Program Director

LIVING KIDNEY DONATION

The first living kidney donation occurred in 1954. Today, over 40% of all kidney transplants come from living donors. This booklet is designed to give you information about living donation and the other options available for people suffering from kidney disease.

THE ROLE OF THE KIDNEYS

The kidneys are two bean shaped organs, each about the size of your fist. They are located in the middle of the back on either side of the spine and receive about 20 % of the blood pumped by the heart. The kidneys play a very important role in the body. They are responsible for regulating the content of the blood by controlling water volume and removing waste. They also regulate blood pressure, maintain calcium balance in the body and play a role in the production of red blood cells.

KIDNEY FAILURE AND TREATMENT OPTIONS

Kidney failure can be a gradual process and symptoms may not be seen until the disease is very advanced. Kidney failure occurs when the kidneys are no longer able to remove waste and maintain fluid balance in the body. Without some form of treatment, this would result in death. The two types of treatment for kidney failure are dialysis or transplantation.

There are two different kinds of dialysis: hemodialysis or peritoneal dialysis. During hemodialysis, tubes connect the patient to a machine that filters the blood. Hemodialysis is usually done three times a week for 3-4 hours each time. It is usually done at a dialysis center, although in some cases families can be trained to do the treatment at home. People on hemodialysis must adhere to a strict diet, restrict their fluid intake and may feel unwell especially after dialysis.

Peritoneal dialysis uses the abdominal cavity membrane called the peritoneal membrane to filter the blood. During this type of dialysis, a tube is placed permanently into the abdomen. During treatment, a fluid called dialysate is infused into the abdominal cavity. Waste and extra fluid move into the dialysate and after a few hours, the fluid is drained out. This is called an exchange. Patients can do 4-5 exchanges per day, or the exchanges may be done at night with the help of a machine that cycles the exchanges while the person is sleeping.

Kidney transplantation is the third option for people with chronic kidney failure. In a kidney transplant, the donated kidney is surgically

placed in the lower abdominal area and replaces the function of the natural kidneys. The patient's own kidneys are usually left in place. The recipient of a kidney transplant must take medicine for the life of the transplanted kidney to prevent rejection. Kidney transplant recipients must also follow strict schedules for lab testing and doctor visits.

WHERE DO DONOR KIDNEYS COME FROM?

Donor kidneys come from two sources: deceased organ donors or living donors. Deceased donors are people who have suffered brain death after a head trauma or medical problem in the brain such as bleeding. The families of these patients make the generous decision to donate their organs. Patients who are on the transplant wait list are waiting for organs from deceased donors. It is not uncommon for patients to wait many years for a deceased donor kidney.

Kidneys can also come from living donors. There are three types of living donors:

- Living related donors (LRD) are donors who are blood relatives of the recipient. Usually these are parents, children or siblings.
 - Living unrelated donors (LURD) are not blood related and are usually spouses or friends of the recipient.
 - A third type of living donor is called an altruistic donor or non-directed donor. These donors volunteer to donate a kidney to any person in need without knowledge of the recipient. In these cases, the transplant wait list or donor paired exchange can be used to select a recipient.
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BENEFITS OF LIVING DONATION

The optimal time for a person to receive a living donor transplant is before they ever start dialysis. There are important benefits of living donation:

- The opportunity to plan the transplant before the recipient needs dialysis. Research shows that the less time a person is on dialysis, the longer a transplanted kidney will function.
- The AVERAGE living donor kidney works for about 15 years, while a deceased donor kidney lasts about half that long.
- Another benefit of living donor transplants is they can be planned for convenience and timed to insure the best condition of the recipient at the time of surgery. This also avoids the 2-5 year waiting period on the deceased donor list.

MATCHING AND COMPATIBILITY

You may have heard discussions about “matching” and kidney transplantation. There are actually three tests that are done to evaluate donors. They are blood type, crossmatch, and HLA testing. This blood test is the first step in the process of living donation and determines if you are compatible or a “match” to your recipient.

Blood Typing

There are 4 different blood types. The most common blood type in the population is type O. The next most common is blood type A, then B, and the rarest is blood type AB. The blood type of the donor must be compatible with the recipient. The rules for blood type in transplantation are the same as they are for blood transfusion. Some blood types can give to others and some may not.

Blood type O is considered the universal donor. People with blood type O can give to any other blood type. Blood type AB is called the universal recipient because they can receive an organ or blood from people with any blood type. The chart below shows which blood type can donate to which.

If your blood type is:	You can donate to these blood types:
Type O	Type O, A, B, AB
Type A	Type A, AB
Type B	Type B, AB
Type AB	Type AB

HLA Typing

HLA typing is also called “tissue typing”. HLA stands for human leukocyte antigen. Antigens are proteins on the cells in the body. Out of over 100 different antigens that have been identified, there are six that have been shown to be the most important in organ transplantation. Of these six antigens, we inherit three from each parent.

Except in cases of identical twins and some siblings, it is rare to get a six-antigen match between two people, especially if they are unrelated. The chance of a perfect or six-antigen match between two unrelated people is about one in 100,000. Kidneys are commonly transplanted between two people with no matching antigens without a rejection episode. In other cases where all six antigens matched, recipients have suffered from rejection. There is no way to predict who will experience a rejection episode. Living donors with a 6 antigen match do allow the opportunity for decreased immunosuppression.

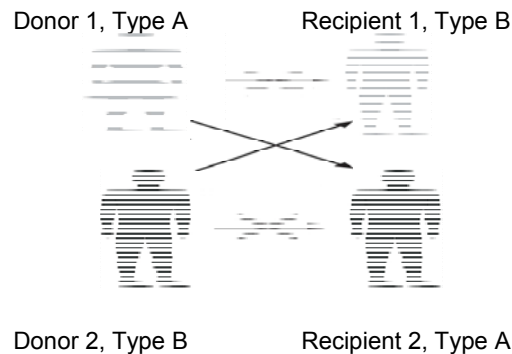
Cross-Match Testing

The crossmatch test is a very important part of the living donor work-up and is repeated again just before the transplant surgery. Blood from the donor and recipient are mixed. If the recipient’s cells attack and kill the donor cells, the crossmatch is considered positive. This means the recipient has antibodies “against” the donor’s cells. If the crossmatch is negative, the pair is considered compatible.

PAIRED DONATION

There are times when a living donor is incompatible with the intended recipient either because their blood types are not compatible or they have an incompatible crossmatch. An option for this situation is called paired exchange. In paired exchange, information about the incompatible donor and recipient are placed in a computer system that identifies other incompatible pairs. The idea is that an exchange of

donor to recipient takes place and both receive a living donor transplant.



DONOR MEDICAL EVALUATION

The purpose of the donor medical evaluation is to make sure that donation will not pose any unusual risk to you during the procedure, or risk to your future health.

Once we are informed of your interest in donation, we will ask that you complete a health questionnaire. It is very important that you are completely honest in answering these questions. The information you share will be kept confidential. The living donor nurse will review the information on your questionnaire and contact you to discuss donation in more detail.

You will be required to have medical insurance and establish with a primary care doctor before starting a donor evaluation to ensure continued medical follow-up after donation.

Once the nurse has cleared your questionnaire, blood typing and crossmatching will be done. The lab needs blood from both the donor and the recipient to do the test. The quickest way to get it done is for the donor and recipient to go to the lab together. If that is not possible, your visit to the lab must be coordinated with the recipient blood draw.

When compatibility is confirmed, the remaining tests will be scheduled. A urine collection and blood test will be done before your visit to the transplant center. The evaluation testing takes two to three days and will include the following:

History and Physical

The history and physical is like an annual visit to the doctor. The doctor will go over the information on the health questionnaire and do a physical exam. The purpose of the exam is to determine whether your general health is good and there are no unusual risks to donation.

Psychosocial Interview

During the psychosocial interview you will talk with the clinical social worker who serves as the independent donor advocate. This visit is a very important part of the living donor evaluation. The goals of the psychosocial interview are:

1. To identify any potential emotional risks to you as a donor;
2. To ensure that you understand the risks, benefits and potential outcomes for you and your recipient;
3. To determine that you are capable of making the decision to donate and cope with the stress of a major surgery;
4. To explore your rationale for donation and to be sure you are free of pressure, guilt, etc;
5. To discuss how donation might impact your job or family relationships;
6. To ensure you are able to understand and comprehend the information provided to you;
7. To explore current / past history of psychiatric disorders and treatments;
8. To review the nature of the relationship between donor and recipient;
9. To determine that the support systems are in place and you have a realistic plan for recovery;

10. To be sure you have received and understand information about the risks of complications, recovery phase, and financial ramifications of donation;
11. To reinforce that if you wish to decline at any time, the transplant center will provide a general statement of unsuitability;
12. To reinforce that the transplant center will not discuss the donor evaluation with the potential recipient.

If you have a history of depression, anxiety or any past psychiatric diagnosis or have ever taken medication for any of these problems, you may be asked to see the transplant psychiatrist.

Dietician

You will have a consultation with the dietician to discuss ways to maintain a healthy weight after donation.

Education

Included in the schedule of appointments during the evaluation is a presentation by the living donor nurse coordinator. This one hour class provides education about all aspects of living donation. This class is open to all who wish to attend (family and friends) and is an opportunity to ask questions in an informative and relaxed setting.

Blood Tests

Many blood tests will be done to give us information about the general condition of your organs. The blood tests will screen for diseases of the liver, kidneys, heart and blood.

Urine Tests

A urine test will be done to check your urine for obvious signs of kidney disease or infection. In addition, you will be collecting your urine at home for a 24 hour period. This collection will give us much

more information on the function of your kidneys. When you turn in the urine collection, your blood will also be drawn.

Electrocardiogram

The EKG is done to evaluate the whether the heart rhythm is normal.

Cardiac Testing

If a donor is over the age of 50, more extensive testing is done to rule out heart disease. Usually this is an exercise test during which you walk on a treadmill while the heart is monitored.

Chest X-Ray

A chest x-ray will be done to rule out lung disease or lung tumors.

Colonoscopy

Donors over the age of 50 will need to have a colonoscopy to rule out colon cancer. This is a routine part of health maintenance and is recommended for all adults. This test should be done through your primary care doctor.

CT Angiogram

This test, also known as a CAT scan, is done to evaluate the anatomy of the blood vessels going to and from the kidneys and to screen for kidney stones. This test helps the surgeons decide which kidney to remove.

During this test an IV line will be placed and a contrast iodine solution will be injected into your IV to help show the vessels clearly. The contrast solution will give you a “warm all over” feeling when it is injected. This procedure takes about an hour.

Pap Smear and Mammogram

Female patients will need a pap smear and those over the age of 40 will also need a mammogram. These tests are a routine part of healthcare maintenance and should be arranged through your primary care doctor.

Test Results

When all of the evaluation studies are completed, the results will be reviewed by the transplant team. Once approval is given by the team, the surgery can be scheduled.

SELECTION CRITERIA

Each transplant program is required to have criteria for the selection of both recipients and donors, and patients are required to be provided with this information. The following are the criteria for the selection of living donors.

1. **Age > 18:** Our program will not consider donation from individuals under the age of 18.
2. **Smoking:** There are many known health risks from smoking. Surrounding a surgical procedure, smoking can cause potentially life-threatening respiratory complications during or immediately after anesthesia. Smoking may also increase the risk of developing blood clots in the leg veins which can break loose, travel to the lungs and potentially cause death. Smoking causes increased mucus production and a decreased ability to clear the lungs which can lead to pneumonia. Smoking also causes heart and vascular disease. Smoking causes decreased wound healing. Candidates will not be considered for donation unless they have been tobacco free (including chewing tobacco) for at least 8 weeks prior to donation and smoking is *strongly discouraged* after donation to protect long term health.

3. **Drug Use:** Potential donors must not use any illicit drugs. This includes periodic use of any drug such as marijuana in any form (including orally). Potential donors who use chronic pain medication experience a higher incidence of post-operative pain after donation. These individuals may be requested to see a surgeon and/or psychiatrist prior to being considered for donation. The transplant team may request random drug screening if there is concern regarding drug use. Failure to comply with requests for drug screening would be considered cause for declining donation.

4. **Health Problems:** Donors must be very healthy individuals. If a donor has a past history of suffering from the following problems, or if these are discovered during the medical evaluation, a donor may be declined. The RN will discuss the donor's health history in detail before the evaluation begins and the doctor will review it again at the first clinic visit.
 - High blood pressure treated with medication (there may be rare selected situations when the team may consider a donor on a single blood pressure medicine).
 - Diabetes. In some cases, young donors may be declined for a very strong family history of diabetes even if the donor does not currently suffer from diabetes, due to the risk of developing it later in life.
 - Gestational diabetes (diabetes during pregnancy). Donors less than age 40 years old with a history of gestational diabetes will not be a candidate for donation. Donors over the age of 40 years old will be considered on a case by case basis.
 - Systemic lupus erythematosus
 - Polycystic kidney disease
 - Substance abuse
 - Psychiatric illness. If a donor has a history of mental health problems including a remote history of anxiety or other common disorders, the team may request a psychiatric evaluation. Donors with current mental health concerns may not be candidates for living kidney donation.
 - Heart / heart valve disease or peripheral vascular disease (disease of blood vessels in the legs)
 - Lung disease with impaired oxygenation or ventilation.
 - Recent cancer or a history of cancer that typically takes a long time to recur

- Low kidney function (usually creatinine clearance of <80ml/min (a test of kidney function).
 - Protein in the urine > 300 mg per 24 hours (a test of kidney function).
 - Active hepatitis B or C infection or HIV infection.
 - Use of medicines that are known to cause kidney damage.
 - History of blood clots or risk factors for the development of blood clots. (use of birth control pills, smoking and obesity are factors that may temporarily disqualify a donor due to the risk of developing blood clots.
5. **Obesity:** Obesity is an independent risk factor for kidney disease. Candidates with a body mass index of over 35 will generally not be considered for donation unless an individual is very muscular. Individuals with a BMI of >25 will meet with a dietitian to discuss strategies to remain at a healthy weight for life.
6. **Psychosocial Issues:** The social worker will evaluate many psychosocial aspects of living donation with the potential donor. Donors may be declined if they have inadequate support for recovery, questionable donor-recipient relationship or motivation for donation, a history of poor coping or psychiatric illness, a history of not taking good care of their health, or other similar concerns.
7. **Insurance coverage and primary care doctor:** It is so important for donors to have good ongoing medical care to monitor the function of the remaining kidney that the United Network for Organ Sharing has recommended that all donors be required to have health insurance and a primary care doctor. Our program supports this position.
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THE INDEPENDENT DONOR ADVOCATE

Transplant programs are required to identify an independent advocate for living donors. This is a person with a good understanding of transplantation whose sole purpose is to:

1. Promote the best interest of the potential living donor.
2. Advocate for the rights of the potential living donor.
3. Assist the potential living donor in obtaining and understanding information regarding:
 - The consent process
 - The evaluation process
 - The surgical procedure
 - The benefit and need for follow-up in six months, one year and two years post donation

The IDA will contact you six months, one year and two years after donation to check on your well-being and to obtain some basic information about your health that all transplant centers are required to report. Please cooperate with your IDA as your health and well-being are the priority.

THE SURGICAL EXPERIENCE

Female Patients

Female patients must be off birth control pills for a minimum of 6 weeks before surgery. Birth control pills have been shown to increase the risk of developing blood clots. An alternate birth control method should be used, and pregnancy testing will occur on the day of the pre-op visit.

Pre-op Day

Many activities will happen the day of your pre-op visit. The donor and recipient will first go to the hospital laboratory to have blood drawn for the final crossmatch and some updated lab testing. The recipient will also have a chest x-ray and EKG, and both donor and

recipient will be seen in the anesthesiology clinic. Both the donor and recipient will be seen in the Transplant Clinic for a pre-operative visit.

If the recipient is on dialysis, he/she will require a dialysis run before the transplant, and the transplant coordinator will make those arrangements.

If you live some distance away from the transplant center, you may wish to stay in a hotel. There is a hotel within walking distance of the hospital. The hotel is Courtyard by Marriott at (916) 455-6800. They offer discounted rates for patients of UC Davis Medical Center if requested and there is room availability. Reservations must be made through the hotel directly, not on-line.

Surgery Day

On the morning of surgery, both the donor and recipient will be admitted to Tower 1, which is the pre-surgery unit. Altruistic donors will not be admitted to Tower 1, rather to an alternate unit. The donor surgery will start first, and the recipient surgery will start shortly after.

Once you are in the operating room, you will receive an anesthetic to put you to sleep. Your abdomen will then be shaved and a catheter will be inserted into your bladder. This allows the doctors to closely monitor your urine output.

The actual surgical procedure for the donor will take about three hours. One kidney with its artery, vein, and ureter will be removed from you and prepared for transplant into your recipient.

Our transplant surgeons use the technique called hand assisted laparoscopic nephrectomy. With this technique, two small incisions and one large enough to remove the kidney are made in the abdomen. Special instruments and a miniature camera are inserted into the abdomen. The camera allows the surgeon to see the kidney on a TV monitor while it is cut free from the surrounding tissues. This technique results in a quicker recovery time as compared with an open incision.

After your surgery is completed, you will be taken to the recovery room where you will awaken from your anesthesia. While in the recovery room, your vital signs and blood tests will be monitored. When you are fully awake, you will be moved to the Transplant Unit. Altruistic donors will recover on a different unit than the recipient.

While you are in the operating room and recovery room, your family can wait in the second floor waiting room or main hospital lobby. Families of altruistic donors will be provided with an alternate waiting area from the recipient family. After the surgery is completed, the surgeon will talk to them and report on the surgery and your condition. Your family may visit you when you return to your room.

Hospitalization

After you return to your room, you will continue to be monitored closely. Your vital signs will be checked frequently and you will be asked to breathe deep and cough periodically. You will still have an IV in your arm, but it will be taken out when you are able to drink fluids. Most donors are able to drink fluids about 24 hours after surgery and are able to eat a regular diet by the second day. The catheter will be left in your bladder for about 24 hours so all of your urine can be measured to make sure your kidney is working well. Blood tests will be done daily to check your blood count and kidney function.

You will experience pain in your abdomen after surgery but you will be given medication to make it more tolerable. You will stay in bed overnight but after that you will need to walk around the unit several times a day. This will help decrease pain and speed your recovery. You will be discharged 2-3 days after surgery.

The IDA will see you in the hospital before discharge to provide you with some written materials about care after donation and plans for follow-up.

Follow-Up Care

After discharge you may continue to have some abdominal pain for approximately one week. You should not lift more than 20 pounds for six weeks, as full recovery from the surgery takes about six weeks. Donors can return to work after six weeks. Some donors who have desk jobs may feel ready to return to work after two weeks. You can resume driving after four weeks and can resume sexual activity whenever you feel comfortable participating.

You will be seen in the clinic by the transplant surgeon and the IDA one week after discharge from the hospital. If you have any problems after that time that are related to your donation, you may call the transplant center and talk to the living donor nurse. You will also be contacted by the IDA at 6 months, 1 year and 2 years after donation.

The transplant team does recommend that living donors avoid long-term use of a class of drugs called NSAIDS. The most common NSAID is Motrin or ibuprofen. These drugs can cause kidney damage over time. They can safely be taken for an injury for a period of two weeks but should not be taken long-term for treatment of problems such as arthritis.

Donors should always receive routine medical care and any treating doctor should know that you have one kidney. The transplant team recommends:

1. A yearly physical exam with height, weight, and blood pressure measurement
2. Yearly laboratory studies with complete metabolic panel and urinalysis
3. That you maintain a normal weight and exercise at least 4 times a week for 30 minutes
4. That you get plenty of rest and eat a balanced diet avoiding saturated and trans fats and avoid excessive salt in your diet
5. That you talk to your doctor before taking any over the counter medications or supplements for more than a few weeks
6. That you avoid high impact sports.

POTENTIAL RISKS AND COMPLICATIONS

Although living donor transplantation is highly successful, short and long-term complications can arise. Because donors are healthy, there is much less risk. However, anyone who has surgery is exposed to some risks. The risks associated with being a living donor include, but may not be limited to the following:

1. Potential for surgical complications such as:
Side effects associated with allergic reactions to anesthesia
 - Pneumonia
 - Blood clots
 - Bleeding, including the need for a blood transfusion
 - Infection
 - Death
2. Potential for organ failure and the need for a future organ transplant for the donor
3. Potential for other medical complications including currently unforeseen complications
4. Scars
5. Pain
6. Fatigue
7. Abdominal or bowel symptoms such as bloating or nausea
8. Increased risk with use of over the counter medications and supplements

The potential psychosocial risks associated with being a living donor include, but may not be limited to the following:

1. Potential for problems with body image;
2. Possibility of post surgery adjustment problems;
3. Possibility of transplant recipient rejection and need for re-transplant;
4. Possibility that the transplant recipient may have recurrent disease;
5. Possibility of recipient death;
6. Potential impact of the donor's lifestyle.

The potential financial risks associated with being a living donor include, but may not be limited to:

1. Personal expenses related to travel, housing, and lost wages may not be reimbursed. There may be resources available to defray

- some donation-related costs. Some insurances offer donor travel benefits.
2. Child care costs
 3. Possible loss of employment
 4. Potential impact on the ability to obtain future employment
 5. Potential impact on the ability to obtain or afford health, disability and life insurance
 6. Health problems experienced by living donors following donation may not be covered by the recipient's insurance.
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OTHER QUESTIONS DONORS ASK

Can I have children after I donate?

Yes. Having only one kidney does not interfere with having babies, however women should wait 6-12 months after donation to get pregnant. Some young parents are concerned that if they donate one of their kidneys and in the future their child needs a transplant, they could not donate to the child. This is a consideration that parents will have to discuss.

What if the kidney does not work?

There is no guarantee that any transplant will work. Recipients could have medical problems that impact the function of the kidney. Sometimes there are surgical factors that may impact the function of the kidney. Sometimes living donor kidney patients suffer from rejection. If a kidney from a living donor is lost, it is very sad and represents a great loss to both the donor and the recipient. However, even in cases where the outcome is not what was hoped for, most donors feel that they have made every effort to help the recipient and feel a great sense of gratification in offering this gift.

How do kidney donors feel about the experience?

In a survey of living donors, 97% of them said they would make the same decision again without any reservation. These donors were also asked about their relationship with the recipient after the surgery. 41% said that they continued to have a close relationship, and 59% felt the relationship with the recipient had improved.

Even with successful transplants, some donors have a feeling of let down after the donation. There is usually a great sense of anticipation before the surgery. After surgery some donors report feelings of let down or frustration. The attention of relatives and friends is often shifted to the recipient and the close monitoring of their organ function. This is natural because the management of your gift is very important. If you experience these feelings, please talk to the living donor nurse or IDA to assist you in working through this.

THE DECISION ABOUT DONATION

The decision to be a living donor involves careful consideration, and you can change your mind at any point in the process. The reasons will be kept confidential. Your decision to donate **must** be voluntary. Donors **may not** be paid directly or indirectly for donating a kidney. Consider discussing your decision with family and friends. You may want to explore your answers to the following questions:

- Do I have enough information to make an informed decision?
- Am I being pressured to be a donor?
- What impact would donation have on my personal relationships?
- Do I have enough support to assist me during my recovery?
- How will potential expenses and/or lost wages impact me?
- Am I prepared to deal with the possibility of recipient complications or loss of the organ?

We hope the information that has been provided in this booklet has answered any questions you had about living donation. If you have additional questions or concerns, do not hesitate to call the Transplant Center at 916-734-2111 or 1-800-821-9912 and speak with the living donor nurse coordinator.