

KIDNEY COACH PLAYBOOK



**Mount
Sinai**

*Recanati/Miller
Transplantation
Institute*

For more information call
The Zweig Family Center for Living Donation
212-659-8024



The Offensive Strategy for a Kidney Coach:

It isn't easy for an individual in need of a kidney to ask someone to consider donating a kidney. The person with kidney failure may be afraid of rejection, afraid that s/he will jeopardize her/his relationship with the individual s/he approaches, or worry that the donor will be harmed.

With that said, a friend or family member of the individual with kidney failure, who may not be able to donate her /his own kidney, may have a strong desire to help in some way. Becoming a Kidney Coach who spreads the word about the patient's condition and the need for a living donor kidney transplant can improve the chance that a suitable donor is found!

Athletic coaches assist athletes in developing their full athletic potential. Similarly, Kidney Coaches assist patients with kidney failure in reaching their full physical potential, allowing patients to live their fullest lives through live kidney donation. As a Kidney Coach, **you** are the primary advocate and spokesperson for the patient with kidney failure. Your job is to let everyone within the patient's circle of family, friends and community know about the patient's battle with kidney failure and all of the transplant options available including dialysis, deceased donor transplant and living donor transplant. As the Kidney Coach, **you** encourage those who are interested in becoming a living donor to connect



with the Mount Sinai living donor team to learn more about donation.



The Kidney Coach
makes things happen!
You should be proud to hold this position on
the kidney team:

As the Kidney Coach, you are an essential member of the patient's support team. Just as the patient needs a transplant surgeon, a registered nurse and a donor, the patient may need a designated advocate to find a living kidney donor, which is the best option for transplantation. **You** serve as the patient's primary advocate. **You** create the right conditions for friends and family to learn about kidney failure and motivate these

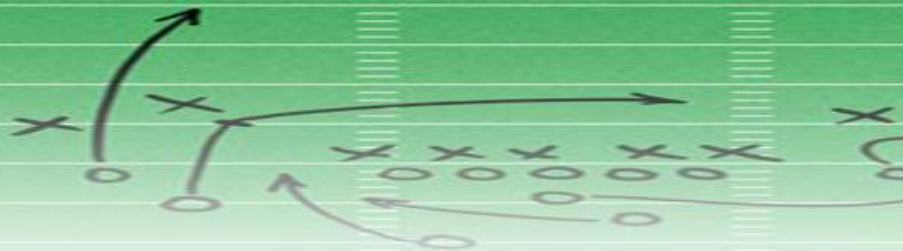


individuals to consider donation.

Someone must take the lead in reaching out to others to find the living donor, *while at the same time*, will need energy to provide the patient with hope, support and encouragement before, during and after the transplant surgery. A donor cannot provide this kind of holistic support. For this reason, **you** as the Kidney Coach play an essential role on the patient's kidney team.



"Every accomplishment starts with the decision to try" – Gail Devers, former three-time Olympic Champion in track and field for the US Olympic Team



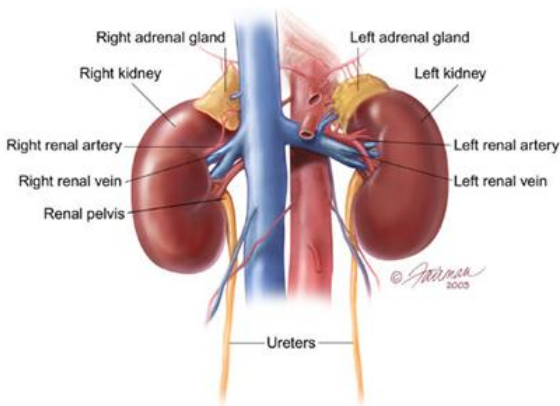
Offensive Strategy #1: **Be informed about Kidney Failure**

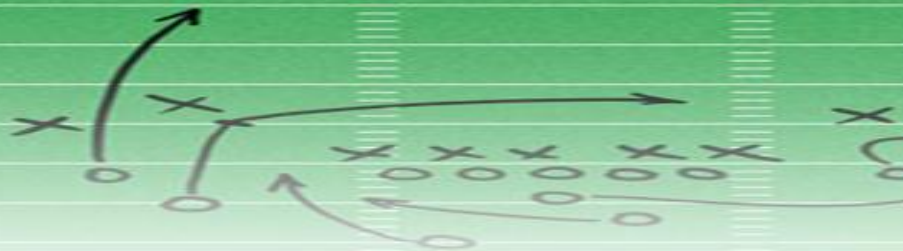
Our kidneys perform many important functions including:

- Filtering and removing waste by making urine
- Helping to regulate blood pressure
- Cleaning and controlling the amount of blood in the body
- Keeping the body's balance of water, salt, and acid constant
- Making hormones that help to produce red blood cells

Many things can cause kidneys to fail including certain diseases such as diabetes, high blood pressure, and genetic diseases like polycystic kidney disease, nephritis, lupus, vasculitis, kidney stones, kidney cancer, trauma, and medications.

Regardless of the cause, a kidney transplant may be a great option to improve a person's quality of life and help them to live longer.





Offensive Strategy #2: Understand the Benefits of Kidney Transplant

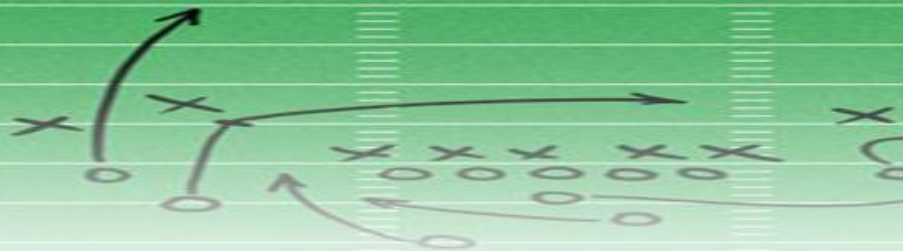
When a person's kidneys begin to fail, they need to be monitored carefully and the patient must follow a strict diet. An individual whose kidneys have failed ultimately needs dialysis to perform many of the functions the kidney used to carry out on its own. It is important to remember that dialysis is not a perfect substitute for the native kidneys and that a kidney transplant is the best option for many patients to treat kidney failure.

Benefits of Living Donor Kidney Transplant **over dialysis** for the patient in need of a kidney transplant include:

- Freedom from dialysis (6 hours, 3 days per week)
- A less restrictive diet
- More energy and time to do things s/he enjoys
- The freedom to travel without the restrictions of treatment (often a person on hemodialysis cannot travel because s/he needs to go to the local dialysis center three times a week and arrangement for the treatment during traveling is not possible)
- An improved quality of life
- Possibly living a longer life

Benefits of Live Kidney Transplant **over deceased donation** for the patient in need of a kidney transplant include:

- Better success rates



- Kidneys from living donors usually have a longer life span and begin to function while the recipient is still on the operating table
 - Living donation helps to avoid the complications of prolonged dialysis
- Shorter waiting time
 - Typically the waiting time in NYC for a deceased donor kidney is 5-7 years
 - 1 out of 20 patients die each year from kidney disease while they wait for a kidney to become available for a transplant

Offensive Strategy #3: **Know the facts about who can be** **a Living Kidney Donor**

A Mount Sinai living kidney donor must be:

- At least 18 years old and less than 70 years old
- Healthy and active
- Able to take time off from work or school to complete the evaluation
- Able to take off at least 2-3 weeks from work or school after surgery

A living kidney donor cannot have any of the following conditions:

- Kidney disease
 - Uncontrolled high blood pressure or take more than one antihypertensive medication
- Diabetes



- Heart disease
- Cancer
- Certain viruses such as Hepatitis C, HIV
- Obesity: BMI >35
- Substance abuse

NOTE: The sale or purchase of human organs is a federal crime and it is unlawful for any person to knowingly acquire, receive or otherwise transfer any human organ for valuable consideration for use in human transplantation

To begin the screening process complete the following survey at: <https://www.surveymonkey.com/s/Be-a-living-donor> or call: 212 659-8024

The results from compatibility testing may determine that a person is not able to give a kidney directly to the patient due to incompatible blood types. This donor can participate in a Kidney Paired Exchange Program (KPD). This requires the prospective donor to list her/his name on a list of incompatible donor/recipient pairs. Sometimes the exchange is with one pair and other times it is through a long chain of incompatible pairs. Donating through an exchange is a way for the donor to help indirectly and also to get others who are in need of a kidney (but who difficult to match) transplanted.



Offensive Strategy #4: **Learn from Experience** **RMTI Donors tell it like it is!**

Please see below for reflections from RMTI Past Donors on Life after Kidney Donation:

“Life after donation...

with two kidneys - played soccer
with one kidney - playing soccer

with two kidneys - rode my horse
with one kidney - riding my horse

with two kidneys - became a reiki master
with one kidney - becoming a yoga instructor

with two kidneys - awoke at four and swam with my dad
with one kidney - waking at four and swimming with my dad

with two kidneys - walked the dog for four miles
with one kidney - walking the dog for three miles and going further each day

with two kidneys - bottom of the donation list (should a need arise)
with one kidney - top of the donation list (should the need arise)





so there you have it...
life after kidney donation...

BETTER THAN BEFORE!"

L.C-R. 3/23/15

"A little more than a year removed from my donation, I feel no different than my two kidney days. If it wouldn't be for the four small scars on my stomach, I probably wouldn't remember it myself. Other than some stamina issues in long runs or bike rides, my physical health and strength have completely returned to pre-surgery levels.

Everyone is different, but my only personal regret is that I don't have another kidney to give - though my wife has encouraged me to give my last remaining one!"

Anonymous 3/29/15

"My life after Kidney donation..."

It's hard for me to say how my life has changed since kidney donation, but rather how donating my kidney has impacted my life.

Since donating my kidney, I think I'm living much more conscious lifestyle. I try to be more aware of what really matters to me



a



and how it will impact my life and others close to me. I know I'm happier and I have learned to not sweat the small things. I'm constantly working towards a healthier regime, eating right, adding some exercise when I can.... this still is a work in progress. The changes I have undergone since donating my kidney have truly been on a much more spiritual level. Because I donated on the basis of a loved one in need, it was a very conscious decision in terms of saving my family; I never gave donation a second thought.

I love the new Toya since kidney donation; I am happy, trying to live life to my fullest potential as well as enjoying the moments. I'm starting to live the life I was always meant to."

T.T. 3/18/15

"I had a great recovery after donating a kidney to my best friend. As you might imagine, I was pretty groggy coming out of surgery but within a few hours I was in my private room with my loved ones. Surprisingly I was encouraged, and able, to walk around a little bit the very same day of the surgery. The first night was a little tough as my body was adjusting, but the nurses on staff were extremely helpful. The next day I saw my surgeon and other Mount Sinai doctors and walked an entire lap of the floor! By the following day I was discharged and recovering at home. I was able to take short walks, which grew day by day. Within ten days my partner and I went to Cape Cod to relax and continue my recovery. Over the next few weeks my stamina grew by the day and within six weeks I was climbing stairs and getting ready to do international travel. The recovery process is intense, especially at the start but it did amaze me how quickly my body healed. Six months later I'm back to long distance running and enjoying life



to the fullest! I'm so happy I was able to help my friend in this profound way."

D.R. 3/16/15

Offensive Strategy #5:
Your goal is to read the playbook:
Get the word out!

Strategic Play: Arrange a social gathering

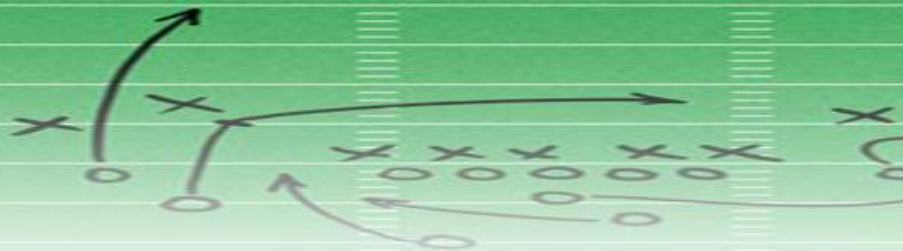
Social Settings where Kidney Coaches could reach out to potential donors:

Invite family/friends/community members to **visit** the patient

- Sometimes when family, friends, others in the community see the patient in need of a kidney face to face and see her/his physical and emotional challenges, the visitors may get a better understanding of the patient's quality of life and feel inspired to support the patient by donating
- Organize a social gathering to celebrate the patient and the patient's strength during her/his fight against chronic kidney disease

Encourage family/friends/community members to go to a local blood drive

- If family and friends donate blood and get their blood tested, some may learn that they share a blood type with the patient in need of the kidney... those individuals then may



more seriously consider donating

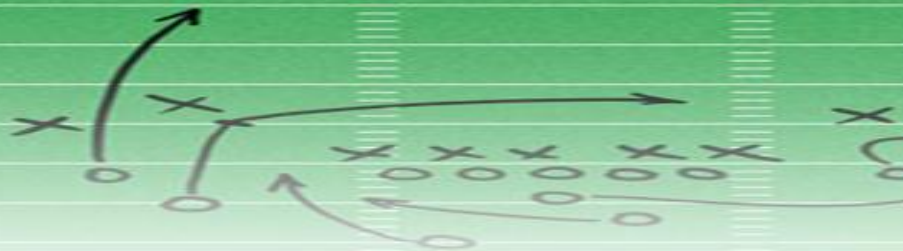
- Meet the family and friends at the blood drive to fill them in on how the patient is doing and answer some questions. If you do not know the answers to the questions, not to worry! Suggest that they contact Mount Sinai's Center for Living Donation (212-659-8024) to learn more about Live Kidney Donation
- Reach out to your Religious or Spiritual Group
- If you and/or the patient is religious or spiritual, touch base with individuals within your/her/his religious community, meet with religious community members before or after a service to discuss the patient's medical situation

"Good players inspire themselves. Great players inspire others" – Unknown

Strategic Play: Write a letter to Friends and Family

This is a successful method to inform a large group of people and give them time to process the situation before asking questions.

Sample letter:



Dear Family and Friends,

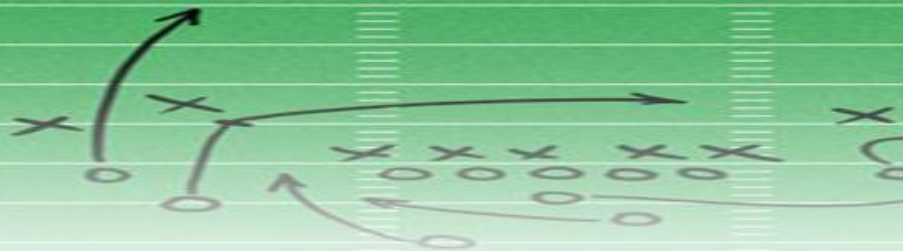
As many of you know, XXXX continues to fight against chronic kidney disease.

After considering her/his options, XXXX has decided to pursue becoming a kidney transplant recipient and is working with the transplant team at Mount Sinai – RMTI to make this happen. In discussion with the medical team, they have suggested that a living donor transplant presents the most benefits and could be her/his best option for the following reasons:

- *Living donor kidneys usually have a longer life span*
- *They begin working immediately*
- *The waiting time is shorter, and you can schedule the surgery based on the donor and recipient convenience*
- *You can plan to have a transplant “preemptively” before starting dialysis*
- *Living donor kidney transplant helps to avoid the complications of dialysis*

We have also learned that in addition to being healthy and wanting help, living donors must be the following:

- *At least 18 years old and less than 70*
- *Healthy and active*
- *Able to take time off work or school to complete the evaluation*
- *Able to take off work at least 2 – 3 weeks after the surgery*



Living donors cannot have any of the following:

- *Kidney disease*
- *Uncontrolled high blood pressure or requiring more than 1 antihypertensive medication*
- *Diabetes*
- *Heart disease*
- *Cancer*
- *Certain viruses such as Hepatitis C, or HIV*
- *Obesity, with a BMI over 35*
- *Substance abuse*

The living donor's evaluation is confidential and will not be shared with me, XXXX, or anyone else on the patient's Mount Sinai team. After becoming educated in regard to the above, XXXX believes that this is her/his best option.

*Anyone who is interested in learning more about becoming a live donor is encouraged to **contact the Living Donor Program directly at (212) 659-8024** to start the screening process.*

XXXX understands that your participation would be a personal choice and appreciates your consideration.

Thank you for your support

Strategic Play: Websites and Social Media Tips



While the Internet can be a valuable resource for medical information, donors are advised to use the Internet with awareness that sometimes the facts about donation may be sensationalized and distorted. Please contact your transplant team with any questions or concerns.

Websites

- Consider creating a website that can inform others about the patient and her/his story!
- Carepages (www.carepages.com) is a website that helps individuals build free patient blogs that connect friends and families during a health challenge to raise awareness about the patient's fight against chronic kidney disease and need for a kidney.





Strategic Play: Websites and Social Media Tips

Social Media

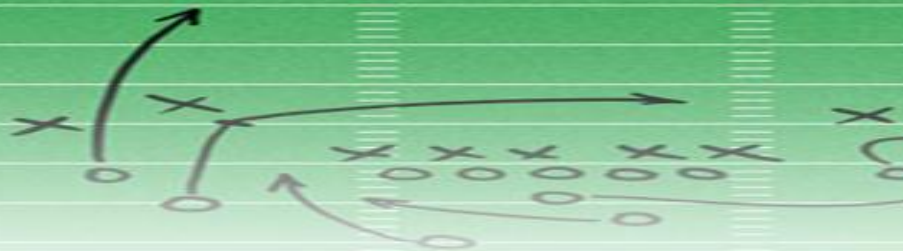
- Create a Facebook page to inform others about the patient and her/his story!
- Please keep in mind that although some strangers do come forward to donate kidneys, most people choose to donate to someone they know. Therefore if you are going to try social media, it is best to first inform close friends and family of the patient's need for transplant. Sometimes just spreading the word to those family and friends who may not have known that the patient is sick will result in prospective living donors coming forward.
- Keep in mind that large media campaigns rarely result in successful donor clearances and can be an emotional roller coaster for a person waiting for a kidney transplant with many prospective donors not proceeding forward with donation. It also utilizes resources in the transplant program which takes away from the screening and evaluation of motivated healthy prospective donors.



Strategic Play: Tips for success in utilizing Social Media

How In order for you to be most successful, please follow the tips below:

- Be honest in your social media campaign, whether it is Facebook, twitter or a flyer, it is crucial to be honest and not stretch truths or omit important information.
- Control your settings for your Facebook request: use personal settings so that you only inform those who are “friends” with you.
- Please **DON'T** put names or phone numbers of the RMTI staff in your post.
- You as the coach should be the initial screener (not the transplant program). Use the inclusion and exclusion criteria listed within this packet to help write your social media post



and screen those not suitable.

- Keep in mind that we can begin screening for donors in any part of country, however, local donors tend to complete the process faster and receive donor follow-up with our team.
- Suitable donors should review education on the Mount Sinai website and complete the online survey to begin the process: <https://www.surveymonkey.com/s/Be-a-living-donor> .

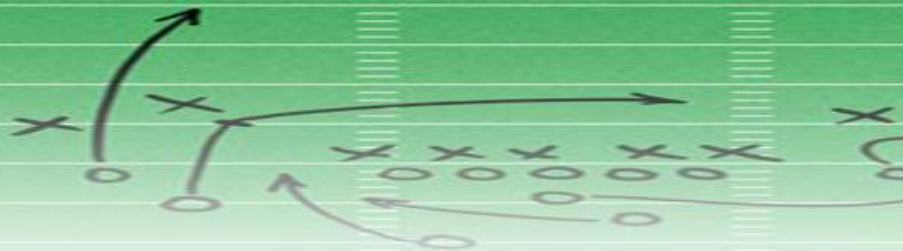
- Our Living Donor Team will reach out to those who complete the screening form to perform the compatibility testing needed (this may need to be done at Mount Sinai Hospital).
- Compatible donors or those interested in Paired Exchange will need to come to Mount Sinai for a comprehensive evaluation.
- Many screenings can be done at once but only **one evaluation** is done at the same time.
- Donors drive the process in terms of length of time to completion. They have a lot to coordinate (finances, time off from work, testing, childcare), it is important not to pressure them to move faster than they feel comfortable. You may jeopardize their willingness to proceed.
- Once a donor is medically cleared surgery can be scheduled.
- Additional Online Campaign support from the Living Kidney Donor's Network: <http://www.lkdn.org/kidneykampaign/index.html>

"The difference between impossible and possible lies in determination" – Tommy Losorda, former Major League Baseball player

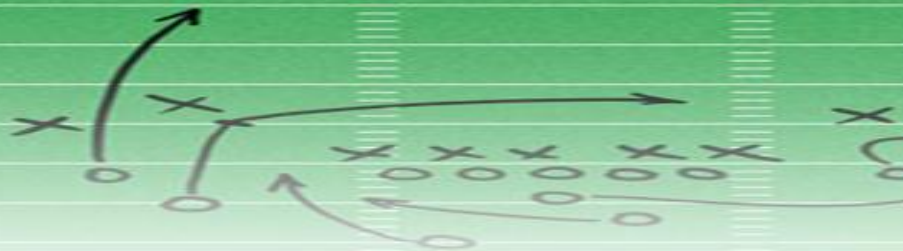


Offensive Strategy #6: Be the Myth Buster

MYTH	FACT
<p>The donor will have many out-of-pocket expenses.</p>	<p>Donors are not responsible for the medical costs of living donation evaluation, surgery, or hospitalization. Medicare and the recipient's health insurance pay for these costs. Some expenses are not covered by most insurance companies. These include lost wages due to time off from work, subsequent childcare expenses, travel expenses, and lodging. There may be federal grants the donor can apply for to cover some of these expenses, so talk with the Mount Sinai Social Worker about such opportunities! Also, Mount Sinai's Living Donor Transplant team may be available to provide affordable housing away from home leading up to the surgery.</p>



<p>Once a donor begins the donor evaluation process, s/he may feel obligated and afraid to change her/his mind.</p>	<p>The live donor team gives potential donors every opportunity to opt out of donation at any point s/he decides donation is not right for her/him. The medical evaluation is confidential and the medical team can provide reasons the prospective donor who no longer wants to donate is ineligible to donate to avoid any discomfort between the prospective donor and the patient in need of a kidney.</p>
<p>Why would one volunteer to be a donor? I will have to convince people to donate.</p>	<p>There are thousands of altruistic donors in United States! There are many individuals who consider kidney donation to be an uplifting experience they would like to take part in to make a difference by extending someone's life.</p>
<p>My religion prevents me from being a donor.</p>	<p>All major religions in the world view organ donation as an act of charity or make it clear that it is a decision to be left up to the individual or family. For a description of the major religions' views on organ donation please view: http://www.donorrecovery.org/learn/religion-and-organ-donation/</p>



<p>If a person does not offer to donate that must mean s/he is not interested in donating.</p>	<p>There is a good chance that many individuals who might be willing to donate are unaware that the patient is in need of a donor! Help spread the word and make the connection.</p>
<p>A donor will have to be on medication for the rest of her/his life.</p>	<p>A kidney donor will be given prescriptions for pain medication and stool softeners at discharge from the hospital. These are only for the immediate post-operative period, after that time, a donor does not have to take medication as a result of being a donor.</p>
<p>A donor will not get health insurance or life insurance after s/he donates.</p>	<p>Due to surgery, donors are advised that health and life insurance companies may increase their rates or even deny coverage. Donors are strongly advised to discuss donation with insurance providers in advance of donation.</p>



<p>A living donor cannot have children post donation.</p>	<p>A woman who donates a kidney may still have children and a male donor can still father children. It is advised that a female kidney donor wait one year after donation before getting pregnant so that her body can heal fully.</p>
<p>The recovery is very long and the donor will need to be out of work for many months.</p>	<p>The recovery tends to involve 1 to 3 days of inpatient hospital stay and the donor is usually out of work 2 to 4 weeks and are back to feeling themselves by 6 weeks.</p>
<p>A kidney donor can no longer participate in sports or exercise.</p>	<p>A kidney donor should be able to return to regular activities and exercise at approximately 4-6 weeks following surgery.</p>

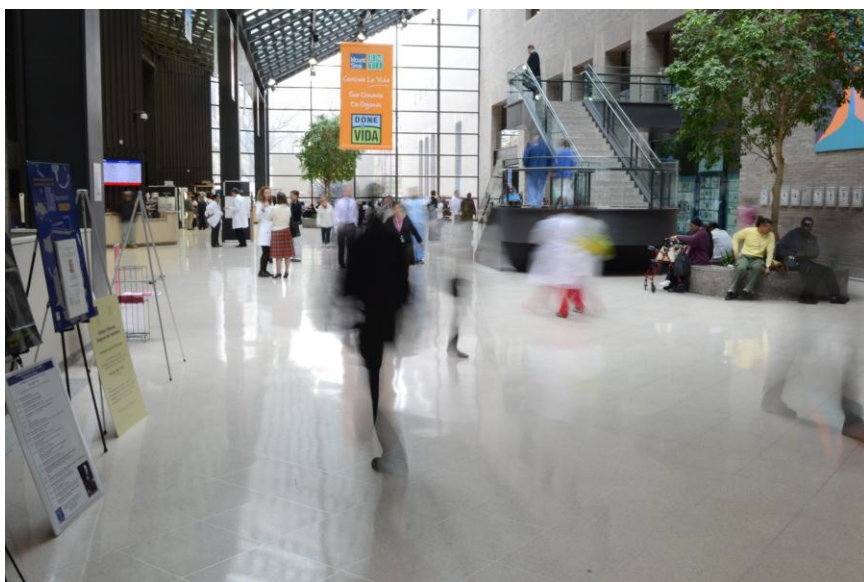
Resources for Myths and Facts section:

- http://www.lkdn.org/kidneykampaign/Myths_About_Living_Kidney_Donation.pdf
- <http://www.donorrecovery.org/learn/religion-and-organ-donation/>
- "Explore Living Donation: Living Donation – What you need to know" An educational Program of Explore Transplant A



Good Luck, Kidney Coach!

Thank you for your support in spreading the word
about live kidney donation



For more information about our Kidney Coach Program
Call us
212-659-8096



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