



# THE BIG ASK: THE BIG GIVE

## A Training Workshop on Living Donation

September 22<sup>nd</sup>, 2019



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# Welcome and Goals



# Why are We Here?



- There are two treatments for kidney failure:
  - Dialysis
  - Transplant
- **Kidney transplant** generally offers more freedom and a better quality of life than dialysis. A transplant can come from:
  - A living donor
  - A deceased donor



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# Why are We Here?



A kidney transplant from a **living donor** typically lasts longer than one from a deceased donor.

As a kidney patient – or a family member/friend of one:

- You may want more **information** about living donation.
- You may need ideas on **how to find a kidney donor**.
- You may need help in **sharing the story** about the need for a donor.
- There are lots of resources that can help.



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# Why are We Here?



This program was created to:

- Provide you with education about kidney donation and transplant.
- Teach you lots of different strategies to find a living kidney donor!

How was it developed?

- The **National Kidney Foundation** developed this program by adapting strategies from the Live Donor Champion program, working with Mount Sinai Hospital who provided additional content, and by identifying additional ideas and strategies from kidney patients, living donors, families, and professionals (including NKF Transplant Task Force members, and NKF Kidney Advocacy Committee members).
- **These are all ideas that worked for other patients and families!**



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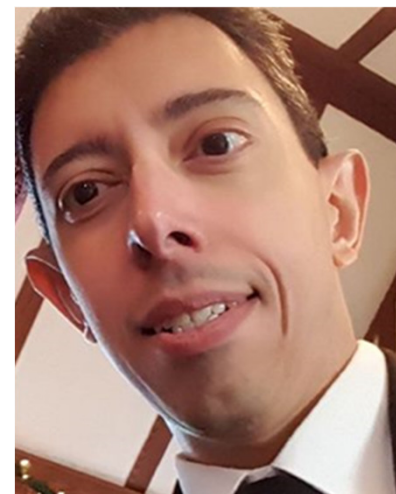
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# This program can help you find a kidney donor!



**THE BIG ASK: THE BIG GIVE program saved my life.** By following the suggestions, I found a donor through my social media network and had a successful kidney transplant. I am so thankful to my donor; and to NKF for helping me find my way to her.”

*- Alan, Kidney Transplant Recipient*



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# THE BIG ASK: THE BIG GIVE



- These training workshops are just one part of NKF's **THE BIG ASK: THE BIG GIVE PLATFORM** designed to increase living donation and transplantation.
- **THE BIG ASK: THE BIG GIVE** includes:
  - In-Person Training Workshops
  - Awareness Campaign
  - [kidney.org/livingdonation](http://kidney.org/livingdonation)
  - NKF Cares Help Line
  - NKF Peers
  - Printed Materials
  - Online Communities



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# Today's Program



- Today you'll learn many different **strategies to find a living donor.**
- These strategies can be used by:
  - Kidney patients
  - Family members and friends
- Family/friends will learn how to be an effective advocate for the kidney patient.
  - Be sure to ask the patient's permission to use the strategies here.



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# 7 Key Strategies to Find a Living Donor



Bust Myths



Build a Network of Advocates



Know the Facts



Learn from Peers



Create Your Story



Create an Action Plan



Spread the Word



# Thank you to our Sponsor!

This program was made possible by a grant from:

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Strategy 1



Bust Myths

True or False?



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# True or False?

A kidney donor and recipient must be related by blood.



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# True or False?

A kidney donor and recipient must be related by blood.



## The Truth:

A donor and recipient don't have to be related by blood. People can donate to family members, friends, or even strangers.



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# True or False?

Kidney donors have to take medicine for the rest of their lives.



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# True or False?

Kidney donors have to take medicine for the rest of their lives.



## The Truth:

A kidney donor will only need pain medicine and stool softeners for a short time after surgery. After that time, a donor doesn't have to take medicine.



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# True or False?

A kidney donor doesn't need the same blood type as the recipient.



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# True or False?

A kidney donor doesn't need the same blood type as the recipient.

## True!

A donor's blood type may not be the *same* as the recipient's, but it may still work well. For example, a person with type **A** blood can donate to a person with type **AB** blood.



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# True or False?

A living kidney donor can't be older than 60.



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# True or False?

A living kidney donor can't be older than 60.



## The Truth:

A living kidney donor can be older than 60 and have no problems from surgery. The kidney from a donor older than 60 can work very well.



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# True or False?

A kidney donor is usually in pain for 3-4 months after surgery.



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## True or False?

A kidney donor is usually in pain for 3-4 months after surgery.



## The Truth:

A kidney donor will have some pain after surgery from the incisions, and from gas and bloating. This pain will decrease in the days after surgery and can be controlled with pain medicine, if needed.



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# True or False?

A kidney donor will usually be in the hospital for about 2 nights after surgery.



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# True or False?

A kidney donor will usually be in the hospital for about 2 nights after surgery.

## True!

A kidney donor is usually in the hospital for only two nights. For example, if surgery is on a Tuesday, the donor will most likely leave the hospital on Thursday.



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# True or False?

A kidney donor won't have to change their diet after donation.



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# True or False?

A kidney donor won't have to change their diet after donation.

## True!

There are no dietary restrictions after donation. A kidney donor can eat anything, but like everyone, should follow a healthy, well balanced diet.



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# True or False?

A kidney donor must be about the same age as the recipient.



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# True or False?

A kidney donor must be about the same age as the recipient.



## The Truth:

Research has shown that transplants can work well when there's an age difference between the donor and recipient.



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# True or False?

A kidney donor can no longer play sports or exercise.



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# True or False?

A kidney donor can no longer play sports or exercise.



## The Truth:

A kidney donor should be able to return to regular activities, including sports and exercise, at about 4 to 6 weeks after surgery.



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# True or False?

A kidney donor can't drink alcohol after donation.



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## True or False?

A kidney donor can't drink alcohol after donation.



## The Truth:

A kidney donor can drink alcohol in moderation.

(That said, drinking too much alcohol is dangerous for anyone, and there is a greater risk for dehydration with one kidney.)



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# True or False?

A female kidney donor can get pregnant after donation.



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# True or False?

A female kidney donor can get pregnant after donation.

## True!

This is true, although the donor should wait 3-6 months after donation to become pregnant. The body needs time to recover from the surgery and to adjust to living with one kidney before pregnancy.



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# True or False?

A kidney donor's sex life will be negatively affected by donation.



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# True or False?

A kidney donor's sex life will be negatively affected by donation.



## The Truth:

A kidney donor can be sexually active when they feel well enough. Sexual libido won't be affected by donation.



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Strategy 2



Know the Facts



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# Benefits of Kidneys from Living Donors



## For the person receiving the kidney:

- Better outcomes than dialysis (or a transplant from a deceased donor).
- Kidneys from living donors typically work better and last longer.
  - A kidney from a deceased donor lasts an average of 7 years.
  - A kidney from a living donor lasts an average of 15 to 20 years.
- Don't need to wait for a deceased donor.

Removing a patient from the waiting list shortens the wait for others.



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# Recovery from Living Donation



Most living donors have laparoscopic surgery, which typically means faster recovery and less pain.

- The usual hospital stay is 1-2 days.
- A full recovery takes about 4 to 6 weeks. Most people return to work/school after 2 weeks.
- Pain medicine is needed for a short time after surgery.
- There are some risks to living donation, which the transplant team will discuss with you.



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# Living Donation



- Quality of life is typically equal to that of the average adult.
- Evaluation for donation includes a complete physical with the most advanced types of tests.
- Follow-up care is provided.
- A living donor's medical expenses are paid by the recipient's insurance, including Medicare.



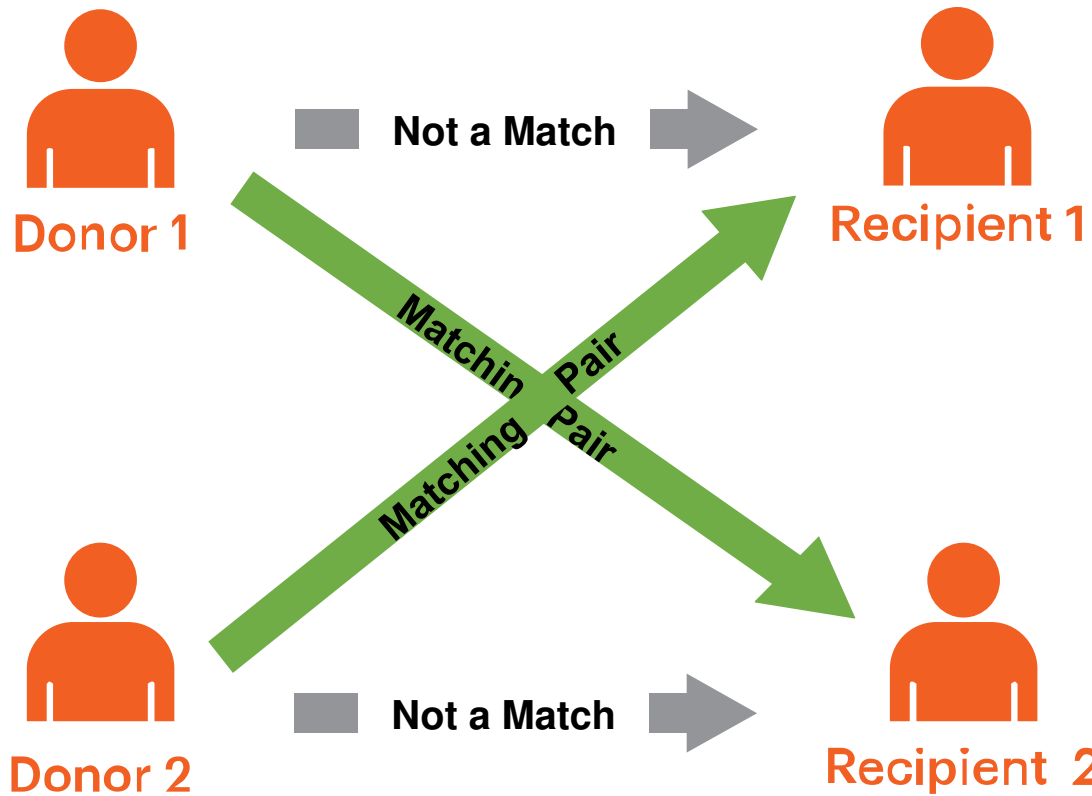
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# Paired Exchange





# Next Steps



## Find potential living donors!

- Anyone who is interested should contact the transplant team.
- **Allow the transplant team to decide if a potential donor is eligible!** Someone you think may not be a good candidate may qualify.
- Once you have an eligible donor, the transplant team will help you with next steps.



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Let's  
Discuss



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# 7 Key Strategies to Find a Living Donor




Bust Myths



Build a Network of Advocates



Know the Facts



Learn from Peers



Create Your Story



Create an Action Plan



Spread the Word



# Strategy 3



# Create Your Story



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# The key to finding a donor is to share your story.

Start with people you know and  
work your way broader.



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# If They Don't Know....



Many people want to remain private and not let people know that they (or their loved one) are sick.

**But if people don't know,  
they can't help you.**



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# Example 1

## Alex (and mother Bobbie)



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# Example #1 for Discussion



Alex, the son of **Mike Reed '76**, is in need of a kidney transplant. The doctors say that a living donor organ would give Alex the best outcome because of his young age.

*Continued on next slide*



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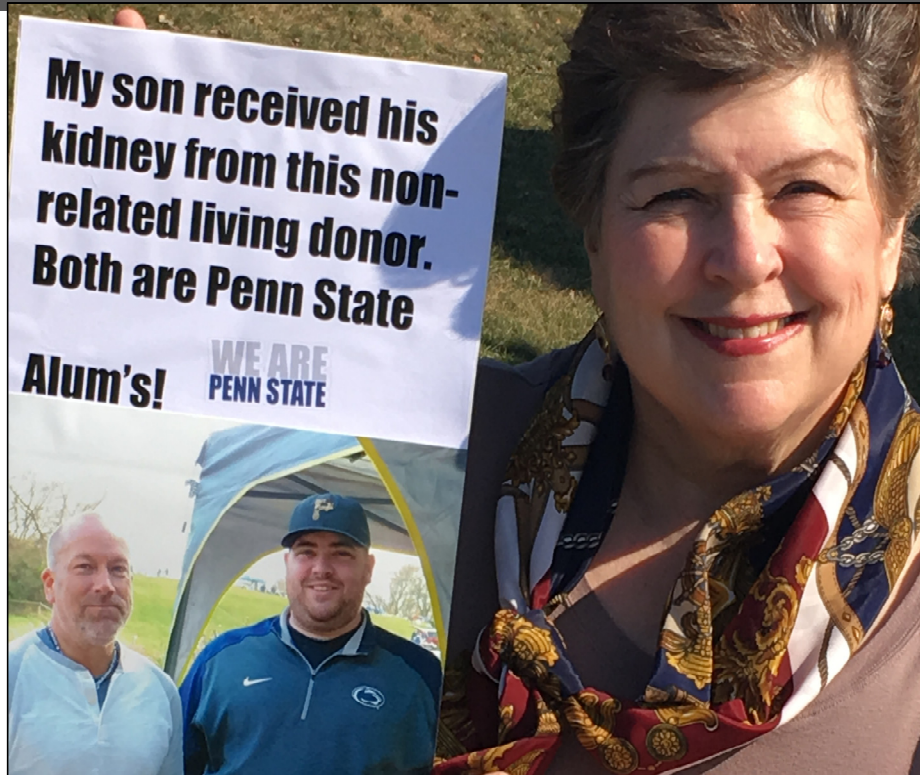


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# Example #1 for Discussion



“When the alumni e-newsletter agreed to share Alex’s story, it was the last in a string of tireless attempts to find a living donor. From church groups to insurance agencies and social media posts, **I didn’t leave any stone unturned.**”

My cries for help went unanswered. **Until the phone rang.”**



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# Example 2

## Alan and Aisha

# Example #2 for Discussion



I was born with Polycystic Kidney Disease (PKD). I inherited this disease from my father. In late 2015, right after celebrating my one year wedding anniversary, my doctors told me that it is time to start my kidney transplant journey.

Many of you who know me well know that I'm not one to openly share my private life and prefer to keep things moving on my own terms and without fanfare. As much as I want to fight the good fight on my own, it's no longer realistic without the help of others. For the sake of my family—particularly my lovely wife, I am reaching out for help. *Continued on next slide* 



The full example is in your packet!



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# Example #2 for Discussion



I am in the process of searching for a living donor. I am also on the kidney transplant waiting list but the wait is long. My blood type is O+. You can help me fight this fight in several ways:

1. Spread the word to your family and friends who might know someone who is willing to serve as a donor. You can start by simply sharing this message on Facebook.
2. Prayers and positive support for me and my family are always welcome and much appreciated.
3. It is not my place to ask you for your kidney—that is a very powerful and personal gesture for you to even consider-- however, I would be humbled and grateful for such a selfless gesture.
4. You can learn more about donation from the National Kidney Foundation at [www.kidney.org/transplantation/livingdonors](http://www.kidney.org/transplantation/livingdonors).

*Continued on next slide*



The full example is in your packet!



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# Example #2 for Discussion



I want to extend my time on this Earth to continue to explore new avenues of my career, enjoy my still young marriage with the love of my life and expand our family unit, enjoy watching my nieces and nephew grow up, and--if it is not too much to ask for--watch my beloved NY Rangers win at least one more Stanley Cup-- now I know that I'm asking for too much right!?

Thanks for reading this message!



The full example is in your packet!



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Let's  
Discuss

- What was included in the messages? What key points or important information was included?
- What do you think made these messages work?



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# Starting My Story worksheet

(a 10 minute exercise)



- **The key to finding a donor is to share your story** (as a patient OR family/friend of a patient).
- Find the “Starting My Story” worksheet in your packet.
- Jot down ideas and thoughts. There are no “right” answers.
- **No one will see your worksheet but you**, so be honest even if some parts of it are difficult to answer.
- **After 10 minutes**, we’ll talk about how you can use this to find potential donors.



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# Discussion



- How did it go?
- How do you think you could use this?



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# Strategy 4



# Spread the Word

# Sharing Your Story... Ideas from Patients and Families



## Bobbie *Mother of a kidney patient*

Her ideas:

- Create a **flyer** or **business card** about the need.
  - Hand out to people you know, people in the community, groups you belong to
- Share with your place of worship (**bulletin, newsletter, ask someone to speak during the service**).
- Share with other groups – for example, **school newsletter**.
- Share the story continuously on **social media** and ask people to consider donation OR just help you share the post. Thank them when they share it!



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# How Do You Spread the Word?



“We found success through key people/organizations we are involved with. Anytime someone posted, printed or did anything to help spread the word, I reposted onto Facebook, thanked the supporter on Facebook, and then asked my friends to share the post.



Our donor was found through this process. It wasn't one particular post. **It was the constant reminder of our need and the sharing of the posts.**”



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# Sharing Your Story... Ideas from Patients and Families



## Alan and Aisha *Kidney patient & wife*

Their ideas:

- Share the story on **Facebook** to “friends of friends” that you’re connected to (not the general public).
- **Include a photo.**
- **Ask family/friends to help “spread the word”** and share the post.



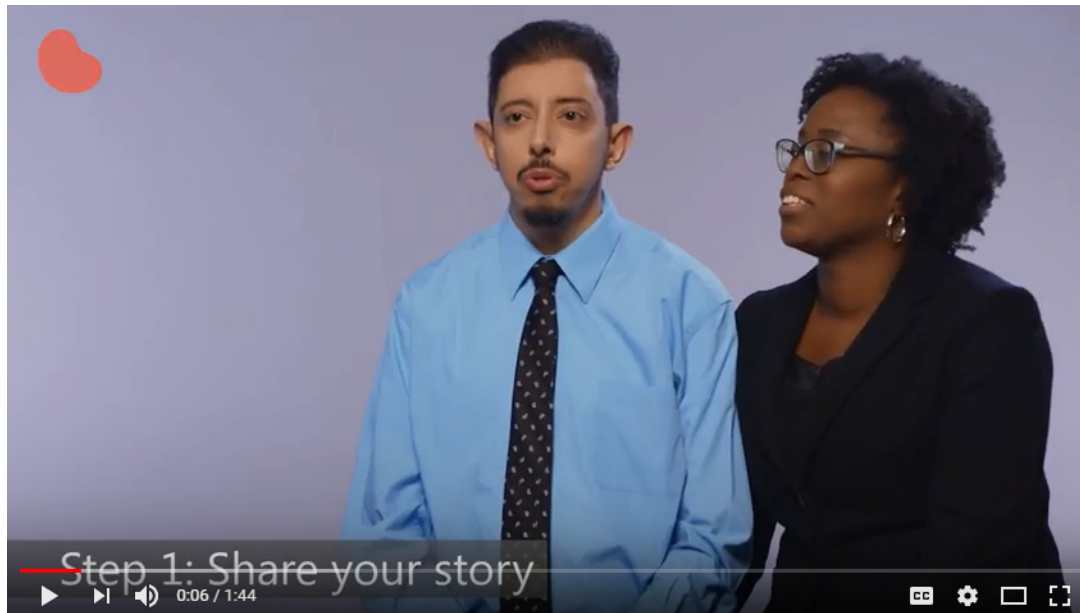
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# Tips for Creating Your Story



Play Video at: <https://www.youtube.com/watch?v=-f5yuW9bmtY>



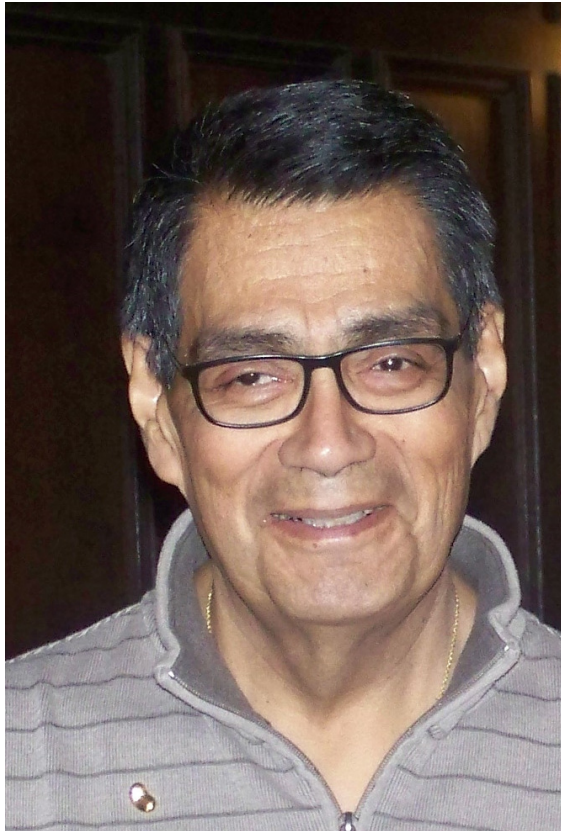
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# Sharing Your Story... Ideas from Patients and Families



## Joe *Kidney patient*

His ideas:

- Set up a **blog/web page** to share the story.
  - Through his blog, Joe provided ongoing updates about his health, his need for a kidney, and what dialysis was like for him.
- Tell people you know! A **church friend** donated a kidney to him.



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# Sharing Your Story... More Ideas from Patients and Families



- **Talk to family/friends** when you get together (social events, reunions, etc.)
- Send an **email or letter** to people you know.
- **Host a social gathering** to talk about the need, distribute flyers, and ask people to help spread the word.
  - Even if they can't donate themselves, they can help by telling others!
- **Speak at a community group** (clubs, hobbies, your volunteer group). Approach groups and community leaders ahead of time.
- **Include a photo** whenever you can! **Make it personal, and also include some facts about donation.**



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# Use your Time Wisely



- Most people donate to someone they know.
- Start by targeting friends, family, co-workers, neighbors, acquaintances and community members.
- **Spread the word to those who don't already know that you (or your loved one) needs a kidney!**
  - **This can result in living donors coming forward.**
- Large media campaigns (like billboards & TV shows) are rarely successful and can take up valuable time and resources.



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# Tips for Creating Your Story



- **This isn't a one-time thing!**
  - It's best to continuously share updates and information over time.
  - Keep asking people to consider donation.
  - Keep asking people to help spread the word.
- **Include other ways people can help (other than donating)** – for example:
  - Spread the word & be an advocate for the patient
  - Bring food
  - Provide rides to medical appointments
- **Provide contact information** (what do they do if they're interested?)



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Let's  
Discuss

- Which strategies do you think you can use?
- What do you want to try?
- What can you ask others to try?



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# Talking to Your Network



- Be prepared – have a plan and know your facts.
- Be direct and honest about the need for a kidney – avoid making a demand or judgement.
- Be clear and concise – use simple language.
- Be an active listener – be aware of non-verbal communications.
- Be available for follow-up questions.



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# Starting the Conversation



- Start with the story (about you OR your loved one's kidney disease).
- Share general information about kidney disease, transplant and living donation.
- Accept that each person may react differently.
- Even if someone is interested, they may need time to think it over.
- If they aren't able to donate, they can still spread the word to others!



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# Conversation Starters



*“I would like to talk to you about something important. Let me know when you have time to chat.”*

*“You know my cousin, John? He has kidney disease and is on dialysis, which is a huge burden to him. He is waiting for a kidney transplant and was told it will take approximately 8-10 years unless he finds a living donor.”*

*“I was told I’m not able to donate a kidney for Sue so I am trying to spread awareness about her need for a kidney. I am hoping that sharing her story might inspire someone else to possibly donate a kidney to her.”*



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# Conversation Points



- *“Dialysis is a huge burden and makes John’s life much more difficult.”*
- *“The doctors say that a kidney transplant from a living donor is the best treatment option.”*
- *I’m helping John by spreading the word that he needs a kidney. Can you help me spread the word, too? Here’s a flyer about his situation.*



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# Closing the Conversation



- *“Thank you for listening and for having this conversation with me. If you have any questions, please don’t hesitate to ask.”*
- *“I appreciate that you let me speak to you about this. It truly means a lot that you listened”.*
- *“Please share this information with anyone you think may be interested in getting evaluated or learning more.”*



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# Common Concerns



*“Do I have the right to ask others to donate?”*

- You are an advocate, and you have the knowledge to share.
- You need help (or your loved one does).
- You don't have to ask them to donate – you can start by simply sharing information.
- You can direct people to NKF for more information about donation.

*“What if I make people uncomfortable?”*

- You don't need to ask people to donate. You can simply tell the story (share the need) and ask people to help you spread the word.



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# Conversation Starters

(a 10 minute exercise)



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# Strategy 5



# Build a Network of Advocates



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# Build a Network of Advocates!



**You don't have to do this alone!** Again, ask people for help:

- “Would you share this flyer with your (place of worship, knitting group, book club?)”
- “Can you share this on Facebook?”
- “Can you ask your (rabbi, pastor) to include something in the weekly bulletin? I can give you the wording to be included.”
- “Can you let people know that \_\_\_\_\_ is waiting for a kidney?”



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# Who Should I Talk to?



Who's in your social network or circle of influence?

- Family
- Friends
- Neighbors
- Co-workers
- School/alumni
- Your house of worship or religious group
- Recreational groups
- Sports teams
- Community groups
- Volunteer/charity groups
- Clubs or civic organizations
- Hobbies (golf, knitting club, etc.)



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# Circles of Influence worksheet

(a 5 minute exercise)



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# 7 Key Strategies to Find a Living Donor



 **Bust Myths**

 **Build a Network of Advocates**

 **Know the Facts**

 **Learn from Peers**

 **Create Your Story**

 **Create an Action Plan**

 **Spread the Word**

# Resources from University of Chicago



## Transplant Outreach, Education and Events

- Transplant education at dialysis units throughout Illinois & Indiana
- Patient advocacy and outreach opportunities
- Transplant and organ donation events

### For more information contact

Claire McGivern, MPH  
cmcgivern@bsd.uchicago.edu  
(773)834-7365

## Living Donation Education and Events

- Living Donor Champion Program
- Living donor appreciation events

### For more information contact

Eliza Tucker, MA  
eliza.tucker@uchospitals.edu  
(773)702-6867



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# Resources from University of Chicago



- Short-term affordable housing during transplant hospital admission, available through IMD Guest house:  
<https://imdguesthouse.org/#>
- University of Chicago Preferred Hotels Program: Discounted hotel rates for patients and caregivers:  
<https://visit.uchicago.edu/accommodations/>
- Discount parking: <https://www.uchicagomedicine.org/patients-visitors/patient-information/directions-and-maps/parking>



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# What should I do when I find a potential living donor?



- At any time after you begin your transplant evaluation, a living donor may come forward to begin their evaluation.
- The First Step:
  - The living donor must initiate contact with the transplant center via:
    - Telephone: Call **773-702-4500** Intake Center
    - Donor Intake Form at: [www.uchicagolivingdonors.org](http://www.uchicagolivingdonors.org)
    - Email: LDChamp@uchospitals.edu
  - You may not contact us for your living donor.



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# NKF Cares



## Have questions? Need help getting started?

The National Kidney Foundation's Help Line, **NKF Cares**, offers support for people affected by kidney disease, organ donation or transplantation. Speak with a trained specialist who will answer your questions and listen to your concerns.

Call toll-free at **1.855.NKF.CARES**  
(1.855.653.2273)

or email [nkfcares@kidney.org](mailto:nkfcares@kidney.org)



## English and Spanish

Monday - Friday from  
9:00 am - 5:00 pm Eastern Time



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# NKF Peers



## For Kidney Patients

- Were you told you need dialysis or a transplant?
- Are you interested in receiving a transplant?

## Living Kidney Donation

- Are you considering donating a kidney to someone?

## Talk to someone who's been there!

Speak with a trained peer mentor who will offer support and share their experiences with you.

Call **855-653-7337 (855-NKF-PEER)** or email [nkfpeers@kidney.org](mailto:nkfpeers@kidney.org) today!



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[www.kidney.org/livingdonation](http://www.kidney.org/livingdonation)



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≡ MENU



## **A CONVERSATION CAN SAVE A LIFE.**

Whether you need a kidney or are considering donation, let us help you start the conversation.



**Christopher**  
Kidney donor

**WATCH THESE REAL AND INSPIRATIONAL STORIES.**

# NKF Online Communities



Connect with other kidney patients, transplant recipients, or living donors through **NKF's online communities**.

- Get answers and support from other patients, caregivers, and living donors in an online forum monitored by NKF.
- Remain anonymous if you wish.

**Transplant:** <https://healthunlocked.com/nkf-kidneytransplant>

**Living Donation:** <https://healthunlocked.com/nkf-donors>



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# Be an Advocate for Living Donation



- The National Kidney Foundation of Illinois collaborates with lawmakers, medical experts, and community leaders to shape public policy on behalf of patients and families affected by kidney disease.
- Every year, we take advocates to Springfield to talk with legislators about upcoming initiatives!
- This year, we passed our first law! The Living Donor Protection Act was signed into law by the governor in August and takes effect starting January 1, 2020.



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# Kidneys in the Kitchen



Kidneys in the Kitchen is a monthly series broadcast on CAN TV and YouTube. Each month the National Kidney Foundation of Illinois and a renal dietitian introduce new, healthy recipes, and offer tips and tricks for making smarter purchasing decisions at the grocery store.



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# Living with Kidney Disease and Transplantation



- A series of FREE educational seminars for people affected by kidney disease, individuals on dialysis, people waiting for a kidney transplant and those who have already been transplanted, as well as their family members and caregivers.
- Chicago North
- Chicago Norte (Español)
- Chicago Central
- Chicago Centro (Español) – October 19
- Champaign Urbana – December 7



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Strategy 6



Learn from Peers

# Living Kidney Donor and Transplant Recipient Panel



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# Strategy 7



# Create an Action Plan

**ACTION PLAN**

Take **a few minutes** to complete your **Action Plan.**



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# 7 Key Strategies to Find a Living Donor



Bust Myths



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Thank you for joining us!

Wrap-Up and Evaluation



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