NATIONAL KIDNEY FOUNDATION®

Participant Booklet

FINDING A LIVING DONOR

The key to finding a living donor is sharing your story — as a kidney patient, family member, or friend. This worksheet is designed to help you develop your story in a way that you can share it widely. Be as honest as you can, as your answers here will not be shared with anyone. Then, you can use this is a "jumping off point" for creating a written story that you can share.

STARTING MY STORY

Here are some ideas of what your story could include:

Intro

Your first name & connection to kidney disease. For example:

- "My name is Alex and I have been waiting for a kidney transplant for 4 years."
- "Hi, this is Maria and I'm writing because my uncle Juan needs a kidney."

Details

Include some personal details about the kidney patient (whether that's YOU or you're writing about a FAMILY MEMBER or FRIEND):

- When diagnosed, how long on dialysis, how long waiting for a kidney
- What's difficult about kidney disease, dialysis, and/or waiting for a transplant
- Hobbies, interests, pets, passions, family, or friends
- What's involved in being a living donor

Conclusion

- How a transplant would help, would it improve the patient's life
- If people are interested in donation, what should they do? (Give contact information for the transplant center or who they should reach out to.)
- Other ways that people can help by spreading the word, etc.

See the "Sample Stories" in your booklet for ideas.

STARTING MY STORY

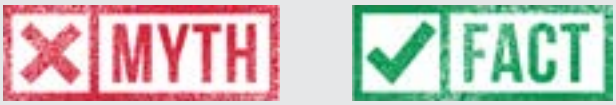
In the space below, start writing some ideas/thoughts about what you could include in your story.

INTRO

DETAILS

CONCLUSION

OVERCOMING COMMON KIDNEY DONATION MYTHS



☒ The donor will have many out of pocket expenses.
☑ **The medical costs are covered by the recipient's insurance. People can apply for grants to help with uncovered costs.**

☒ Once a donor begins the donor evaluation process, that person may feel obligated and afraid to change their mind.
☑ **A donor can change their mind at any time.**

☒ My religion prevents me from being a donor.
☑ **Most religions support living donation. Donors are encouraged to speak with their faith leader.**

☒ If a person does not offer to donate, that must mean the person is not interested in donating.
☑ **Many people don't know that living donation is an option.**

☒ A donor will have trouble getting health insurance/life insurance after they donate.
☑ **There are protections in place to ensure donors have appropriate access to care.**

☒ Living kidney donors won't live healthy lives with just one kidney.
☑ **Donors are at no greater risk than the general population of developing any health related issues to their kidneys and are carefully screened to ensure they are healthy enough to donate.**

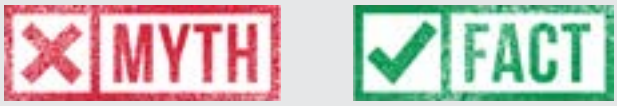
☒ Living kidney donors live a shorter life.
☑ **There is no evidence that donation shortens a person's lifespan.**

☒ Living kidney donors are more likely to get kidney disease after donating.
☑ **Donors are counseled about their individual risk associated with donation.**

☒ Only younger people are able to get kidney transplants.
☑ **All patients who are medically suitable are eligible for transplants.**

☒ Adults over age 50 can't donate.
☑ **Donors must be healthy and can donate primarily on a basis of health, not age.**

OVERCOMING COMMON KIDNEY DONATION MYTHS



☒ Those with tattoos and LGBT people can't be living kidney donors.
☑ **All donors are medically screened for infectious diseases, such as hepatitis, and are only cleared if it is safe for both the donor and recipient.**

☒ A kidney donor can no longer participate in sports or exercise.
☑ **A donor should be able to return to regular activities and exercise about 4 to 6 weeks after surgery.**

☒ Kidney donors will have to take medications for the rest of their lives.
☑ **Generally, prescriptions for pain and stool softeners will be necessary only in the immediate postoperative period.**

☒ A kidney donor will have debilitating pain for an extended period of time.
☑ **Ordinarily, there will be some pain after surgery, which will diminish and can be controlled with pain medication.**

☒ A kidney donor will be in the hospital for an extended period of time after surgery.
☑ **A kidney donor will be hospitalized, on average, for 1 to 2 nights.**

☒ Living kidney donors don't get to choose to the person who gets their kidney.
☑ **A donor can select a person they know and make the decision to donate in a paired exchange with other recipient/donor pairs.**

☒ A donor will have to follow a new diet plan following donation.
☑ **A donor should eat a healthy, well-balanced diet, but there are no dietary restrictions**

☒ A donor can no longer consume alcohol following donation.
☑ **While excessive alcohol use is always dangerous to one's health, a kidney donor can consume alcohol in moderation.**

☒ A female donor should not get pregnant after donation.
☑ **A female donor can become pregnant and should wait until medically cleared after donation.**

☒ A donor's sex life will be negatively affected by donation.
☑ **Donors may engage in sexual activity when they feel well enough to do so.**

SAMPLE STORIES

EXAMPLES

Here are some examples of actual stories shared by kidney patients and families through social media, emails, community newsletters, and other channels.

- For those who may not know, I was born with Polycystic Kidney Disease (PKD). I inherited it from my father, who was in his early 60s when PKD took his life. In late 2015, right after my 1 year wedding anniversary, my doctors told me that it is time to start my transplant journey.
- Many of you know that I'm not one to openly share my private life. 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 your help.
- I am 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:

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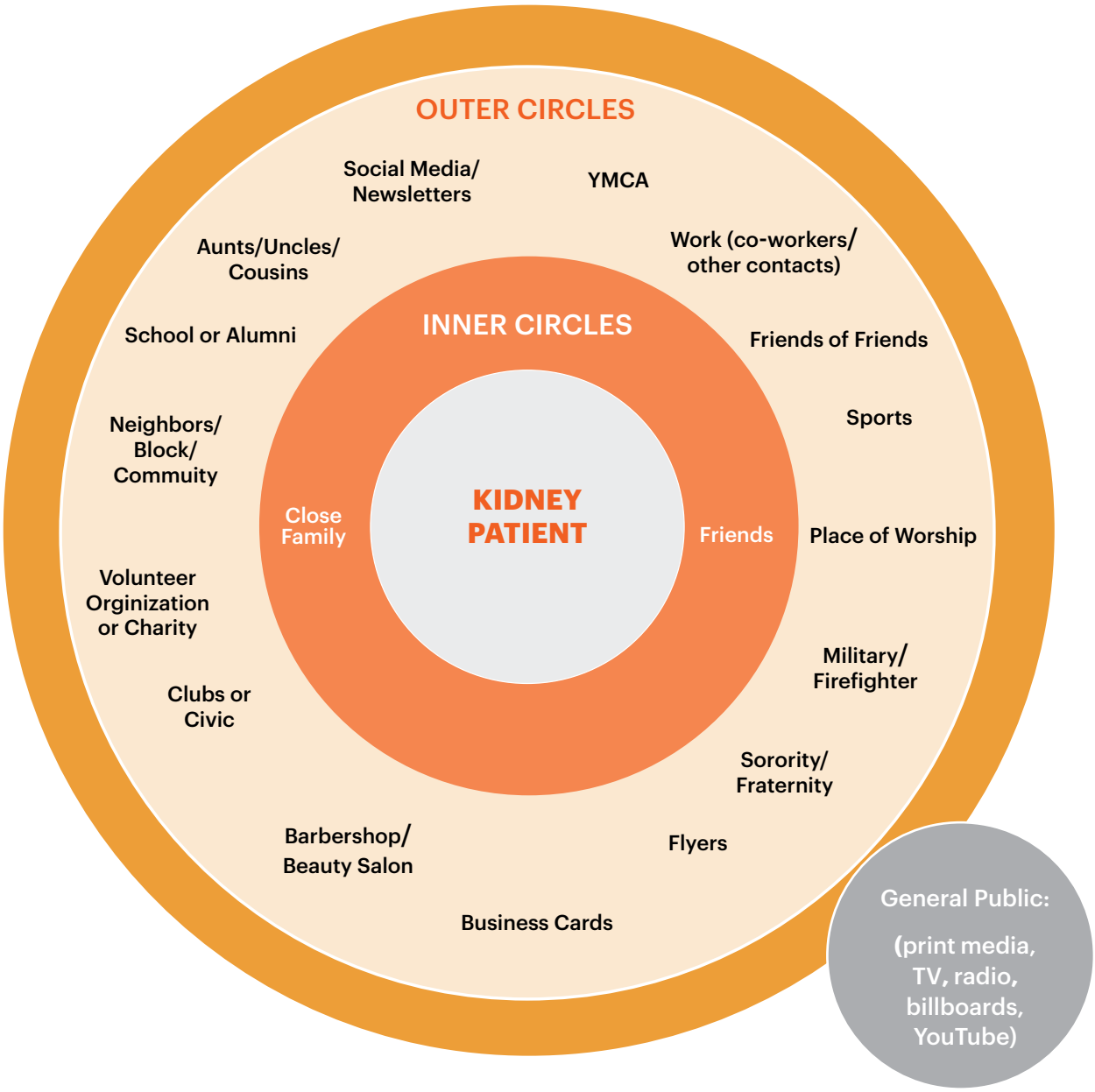
1. Spread the word to your family and friends who might know someone who is willing to serve as a donor. You can start by simply sharing this message on Facebook.
2. Prayers and positive support are always welcome and much appreciated.
3. It is not my place to outright ask you for your kidney — that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

I don't make these requests lightheartedly. I simply 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!

CIRCLES OF influence



MY CIRCLES OF INFLUENCE

Who might consider donating? Who could help spread the word?

List as many individuals and groups below as you can. Think about your personal connections, and those of other family members or friends *(For example: Trey, high school classmate; Carlos' pickup softball league.)*

Friends of friends: _____

My Neighbors/Block community: _____

People I work with: _____

Aunts, Uncles, and Cousins: _____

Members of a place of worship: _____

People at my barbershop or beauty salon: _____

Friends from other community groups: _____

People at my recreation center, gym, or YMCA: _____

Members of my sports leagues: _____

Members of my clubs or civic groups: _____

Military connections: _____

People I volunteer with or do charity work with: _____

Friends from high school or college/alumni: _____

Brothers in my fraternity/Masons: _____

Sisters in my sorority/Eastern Stars: _____

Share on social media (Facebook, Instagram, or Twitter): _____

Make flyers/business cards: _____

Share at social gatherings: _____

Newsletters or bulletins: _____

Blog, webpage or video: _____

Other: _____

TIPS ON SHARING YOUR STORY

Tipa from Jeff, Kidney Transplant Recipient and BABG participant

WHAT KINDS OF INFORMATION DID YOU INCLUDE IN YOUR STORY?

I started including statistics, how many people were on dialysis and on the transplant list nationally and in the state of Pennsylvania. And I could share information about kidney disease with people that were not as familiar with it.

HOW DID YOU START THE CONVERSATION?

Initially, it started off with one on one conversations with individuals about my situation and that developed from there. When someone asked me how I was doing, it would start a conversation. When someone asked me how I was doing, I would mention the fact that I had stage 5 kidney disease. And then it became more of a one on one conversation as opposed to a marketing campaign.

WHERE DID YOU SHARE YOUR STORY?

I'm somewhat of a private person. I'm not out and about a lot. So, when I first started hearing about telling your story, I thought, well, I don't run in those circles or I'm not one that would take a big sign to a baseball game or a football game and say that I needed a kidney. For me it was more one on one conversation eard from, like people from 40 years ago during my college days. Eventually my pastor encouraged me to make a public announcement at church. It wasn't my intention to do a big ask at church, but I wanted to let my fellow worshippers know what was going on in my life. I think I might have even ended the conversation with "if you have an extra kidney in your closet.." And then we basically prayed about it as a church family.

WHAT ELSE DID YOU INCLUDE IN YOUR STORY?

One of the things I picked up from [The Big Ask, The Big Give seminar] was to create an information card that had all the information about how to be tested and who to contact if you were interested in donating. I kept those in my wallet and would hand those out during my conversations, if people asked about how to become a donor.

HOW DID YOU FIND YOUR DONOR?

Eventually there was a beautiful young lady in our church who approached my wife and said, "this is something that had been on our hearts for a long, long time." And this was her opportunity and wanted to learn more. I happened to give her one of the cards and she basically just followed through with it, made a call and went in to be tested and she found out that she was a perfect match.

WHAT IS YOUR ADVICE FOR OTHER KIDNEY PATIENTS?

It's not as hard as you think to tell your story. Everyone has a story and it's not like you have to invent it, make it up, anything like that. All you have to do is be able to communicate it. When someone asks you how you're doing, basically what you're doing, is telling your story.

"SHARE YOUR STORY" CARD

Are you interested

in receiving your own "Share Your Story cards"?

Contact NKF CARES
855.653.2273
nkfcares@kidney.org

Available in English and Spanish

CONVERSATION STARTERS

Here are some ideas of what your story could include:

Opening the Conversation

- "I would like to talk to you about something important. Let me know when you have time to chat."
- "I wanted to let you know that I have kidney disease. I've been waiting for a kidney for about 2 years now."
- "You know my cousin, Marcus? 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 Tracy, 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."

Conversation Points

- "Dialysis is a huge burden and makes Marcus's life much more difficult."
- "The doctors say that a kidney transplant from a living donor is the best treatment option."
- "Did you know that you can live a healthy and complete life with just one kidney?"
- "The evaluation to be a kidney donor is very thorough and paid for by the recipient's insurance."
- "The transplant team won't let you donate unless they determine you are healthy at the time of donation."

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're even considering the option of being a donor and/or willing to learn more".
- "Please share this information with anyone you think may be interested in getting evaluated or learning more."

Donating a kidney can be easier than you think...

...LEARN MORE AT
LEARNINGCENTER.KIDNEY.ORG

TIPS FOR USING FACEBOOK

Creating Your Page

1. Go to: facebook.com/pages/create

2. Click on the "Cause or Community" category.

3. Consider sharing your story (or your loved one's story) in the "About" and "Description" sections:

- Describe the patient's life now and how a transplant could help.
- Describe the kidney patient and who they are (for example: family, work, friends, hobbies, activities, goals).
- Share contact information and/or link for initial screening tool for the transplant program and coordinator.
- Make it as easy as possible for people to make contact by including names, phone numbers, and e-mail addresses if you have them.

Share Your Page

- We suggest making this a "closed page" and sharing it with your friends and friends of friends on Facebook only.
- Post a link to it on your personal Facebook page and ask others to "like" and "share" it. (Not everyone knows how to do this, so be sure to say something like "Click the words 'like' and 'share' directly below.")
- In addition, post your link on the Living Kidney Donor Search page on Facebook.
- Two or three times a week, post status updates, pictures, or general donation information to keep those who have liked your page interested. However, keep it to 2–3 times a week; if you post too many times, people will no longer notice your posts. They may even "unlike" your page to avoid receiving so many posts. Share the link with everyone you know who is on Facebook or willing to join. E-mail is also an excellent way to spread the word to those who aren't on Facebook.

ONLINE KIDNEY COMMUNITIES

YOU'RE NOT ALONE. Connect with others affected by kidney disease. Get support and share your experiences — you never know when you'll inspire someone else!

Understanding

The community encourages discussions on various aspects of kidney disease and health. Connect with other people dealing with the same issues.

Social Media

Just like other social networks (think Facebook, Twitter, LinkedIn, and Instagram), you can create your own profile page, like other people's posts, ask or reply to a question, and follow other people.

Anonymous

The difference with NKF Online Communities is that you can network anonymously and connect with other people who are affected by kidney disease. In the community, you can talk about your health, symptoms, management and much more.

→ KIDNEY DISEASE, DIALYSIS, TRANSPLANT, LIVING DONATION

KIDNEY.ORG/ONLINECOMMUNITIES

WAYS YOUR LOVED ONES CAN BE INVOLVED

Involving your family and friends throughout your transplant journey and recovery is important, and can not only be helpful to you, but also to your loved ones who want to support you. Here are some ways they can help:

- ✔ Meal trains — people can sign up for delivering a meal mealtrain.com
- ✔ Cleaning — a friend or family member might offer to do light house cleaning
- ✔ Grocery shopping — offer to run to the store and bring groceries to you and your family
- ✔ Coming over to visit — spending time with loved ones
- ✔ Playing non-physical games — board or card game while recovering
- ✔ Recommend good moves or TV shows
- ✔ Phone calls — Scheduling regular calls
- ✔ Child/pet care — You won't be able to lift anything heavy for 4–6 weeks, so having someone lined up to help with pet and childcare can be helpful

→ MEAL TRAINS – FRIENDS AND FAMILY CAN SIGN UP FOR DELIVERING A MEAL

mealtrain.com

Most transplant centers will require your care partner to be a friend, family member, neighbor, or someone at your place of worship, etc.

ACTION PLAN

NAME _____

What do I commit to doing next?	I will	I will find someone to	By when?
Finish writing my story using the "Starting My Story" worksheet.			
Share my story on social media – Facebook, Instagram, and/or Twitter. (Please see the handout on setting up a Facebook page.)			
Share my story by email or letter to my Circles of Influence.			
Create a flyer or business card to hand out to my Circles of Influence.			
Find social gatherings to talk about the story.			
Use newsletters or bulletins to share the story.			
Set up a blog or web page about the need.			
Create a video about the need.			
Use community media (Note: talk to the transplant center for advice first).			
Talk to people using the "Conversation Starters".			
Build a Network of Advocates. I'll reach out to at least 5 people to share what I've learned today and ask them to help spread the word: 1. _____ 4. _____ 2. _____ 5. _____ 3. _____			
Ask the transplant center for more information about donation.			
Contact NKF Cares with questions. **(855.NKF.CARES/ nkfcares@kidney.org)**			
Ask NKF for a Peer mentor. **(855.NKF.PEER/nkfpeers@kidney.org)**			
Learn more on the NKF website at **kidney.org/livingdonation**			
Join NKF's Online Communities. (healthunlocked.com/nkf-kidneytransplant and healthunlocked.com/nkf-donors)			
Help others, sign up as an organ, tissue and eye donor at **registerme.org**			
Other actions:			

RESOURCES

There are several resources available to get connected with someone who has already donated. You can visit:

NKF RESOURCES

NKF CARES

Our Patient Information Help Line, NKF Cares, offers support for people affected by kidney disease, organ donation or transplantation. It's designed just for patients, potential donors, family members and care partners. Speak with a trained specialist who will answer your questions and listen to your concerns.

- By phone **855.NKF.CARES** (855.653.2273) or email nkfcares@kidney.org

NKF PEERS

Speak with a trained peer mentor who can share their experiences about dialysis, transplant, or living kidney donation with you.

- By phone **855.NKF.PEERS** (855.653.7337) or email NKFpeers@kidney.org

Online Communities

NKF has 5 online communities for people to ask questions and get answers about kidney disease, dialysis, transplant and living donation. You can find more information at kidney.org/online-communities

OTHER RESOURCES

You can talk to Living Donor team at your transplant center to be connected to previous donor from that center

FINANCIAL RESOURCES

NLDAC

The National Living Donor Assistance center provides financial assistance for non-medical expenses related to donation, including travel, lodging and meals for both the donor and their caregiver. They also offer lost-wage reimbursement for the donor, if eligible. Visit livingdonorassistance.org for more information.

National Foundation for Transplants

offers fundraising assistance for living donors to help with lost wages, travel, food, lodging medications, childcare and other expenses related to donation. Call **901.684.1697**, or email info@transplants.org

ALODF

American Living Organ Donor Fund can provide non-medical financial assistance related to living donation

National Kidney Registery

partners with transplant centers to provide lost wage assistance, financial assistance for travel, life and protections against long-term insurance discrimination, among other protections. Check out which transplant centers partner with NKR. kidneyregistry.org

The National Kidney Foundation is here to help you after the program!

We have resources that can support you after you leave today.

LearningCenter.kidney.org

Check out the Kidney Learning Center for online, self-paced educational videos on living donation and transplant