Living Donor Champion Playbook

Finding a Living Donor: The Fast Track to Getting a Kidney

Helping you get transplanted in less than a year.
Helping you get transplanted in less than a year.

My to-do items:

- X Attend the Living Donor Champion Training session.
- ___ Review all materials (brochures, resources, and more).
- ___ Complete the brainstorm sheet (opportunities).
- ___ Create a plan (Email, mail, Facebook, conversations).
- ___ Give out 10 donor cards (for people to get tested).
- ___ Expect at least 2 people contacted the Transplant Program.
- ___ Plan a date for a living donor transplant and stay healthy.
Learning Objectives

Patients should be able to:

- Describe the risk of death if you stay on dialysis.
- Describe the advantages of getting a living donor transplant.
- Understand what a Living Donor Champion does.
- Take action with the Living Donor Champion Playbook.
So what’s the problem?

Every year...

Only 17,000 people get a kidney transplant out of 120,000+ people waiting on the list.

The average wait time is up to 7 years for a deceased donor kidney.
Patients will die while on dialysis

Statistics show...

6 out of 10 patients will die while on dialysis within 5 years.
Two Options for Transplant

Deceased Donor

Living Donor
## Benefits of Living Donor Transplants

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<tr>
<th></th>
<th>Living Donor</th>
<th>Deceased Donor</th>
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<tbody>
<tr>
<td>Shorter wait times to transplant*</td>
<td>6 months</td>
<td>up to 7 years</td>
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<tr>
<td>How long the kidney will last*</td>
<td>20 years</td>
<td>8 years</td>
</tr>
<tr>
<td>Planning the surgery</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
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*Note: Individual results may vary.*
Living Donation is the Best Option

Myth #1: A kidney donor needs to be related to the recipient.

   Fact: Anyone may consider kidney donation.

Myth #2: A kidney donor will have to take medicine for the rest of their life.

   Fact: A kidney donor does not need transplant medicine.

Myth #3: A kidney donor will have severe pain for a long time.

   Fact: Kidney donors typically only have pain first several days.
Living Donation is the Best Option

Myth #4: A kidney donor will be on bed rest after surgery.

   **Fact:** Kidney donors will be walking before discharge.

Myth #5: Kidney donors will be in the hospital for a long time after surgery.

   **Fact:** A donor is typically in the hospital for 3 – 4 days.

Myth #6: Kidney donors will eventually need dialysis or have a shorter life.

   **Fact:** Living kidney donors live longer & healthier lives than most folks.
Solution: Get the word out

It’s a numbers game.

More conversations = more potential donors.

Facebook posts

Letters and emails

Direct conversations

Get the word out!
You are not alone

90% of patients are reluctant to ask others to be a living donor.

Being hesitant to talk about it is normal.

Someone else can help you to:

- Create awareness by telling your story.
- Mail or email letters to friends and family.
- Have conversations with others.

Get the word out!
Now, you have 2 options:

**Do it yourself.** Start using the champion playbook.

or

**Find a Living Donor Champion to do it for you.**

- As someone to be your champion, your recruiter.
  (It can be more than 1 person)

- Tell them your approved story.

- Have them attend this training.

Get the word out!
What is a Living Donor Champion?

A living donor champion is:

- A spokesperson for the patient.
- Someone who cannot be a living donor (or not willing).
- A recruiter for potential candidates.

When you find your living donor champion:

- Rehearse the story on what they will say about you and what you need.
- Give them materials to hand out to potential donors.
- Agree to discuss progress at least once a month.
### Roles & Responsibilities

**Patient:**
- Takes responsibility for their health
- Coordinates with the Living Donor Champion

**Living Donor Champion:**
- Creates awareness for patient to get a Living Donor
This training is your critical 1st step

This training will help you or your Living Donor Champion:

• Get familiar with materials to promote your need for a kidney.

• Identify people to have discussions with to create awareness.

• Teach possible Living Donors about the living donation process.

• Build your confidence to answer nearly any question… or know where to find it.
Living Donor Champion Resources
Living Donor Champion Resources

LD Campaign Checklist

Brochures

Handouts

Resource List

Brainstorm Worksheet

Sample Letters

Donor Request Cards

Social Media
Living Donor Campaign Checklist

- Name of Living Donor Champion _____________________

- Attended Living Donor Champion Training (Date: ______)

- Reviewed Living Donor Champion Playbook

- Created list of opportunities (see brainstorm sheet p.29)

- What are your next steps?
  - ________________________________
  - ________________________________
Brochures

Learn more about Living Donation
A pamphlet that covers basic information about living donation, donor evaluation, and a story from a living donor and her family.

How to find a Living Donor
A booklet that provides ideas for recipients or Living Donor Champions to find a potential living donor.

Not a Match? There’s Paired Donation
A pamphlet that explains paired kidney donation as an option for potential Living Donors who are found to be incompatible with a recipient. Sometimes referred to as a “swap.”
Living Donation is your best option
(Myth & Fact Sheet)

A handout of common myths and facts about Living Kidney Donation.

Facts About Kidney Donation
Learn Why Living Donation is Your Best Option

Having a living donor can reduce your wait time to weeks, instead of years. Living donor kidneys function better and last longer than deceased donor kidneys. Let’s clear up some common myths about kidney donation.

Myth #1: A kidney donor needs to be related to the recipient.
Fact: Anyone may consider kidney donation. A kidney donor can be a friend, spouse, acquaintance, or someone who does not know the recipient.

Myth #2: A kidney donor will have to take medications for the rest of their life.
Fact: A kidney donor does not need transplant medications. Only people who receive a transplant need to take anti-rejection medications. Shortly after surgery, donors may take pain medications, stool softeners and nausea medicine.

Myth #3: A kidney donor will have severe pain for a long period of time.
Fact: It is normal for a kidney donor to have some pain after surgery for the first several days. This pain will gradually improve and can be controlled with pain medication.

(Over)
## Online Resource List

<table>
<thead>
<tr>
<th>Resource Name</th>
<th>Description</th>
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<tbody>
<tr>
<td><a href="exploretransplant.org">Explore Transplant</a></td>
<td>Supports patients and care providers with educational programs and training seminars. Purpose is to help kidney patients make informed transplant decisions.</td>
</tr>
<tr>
<td><a href="kidney.org">National Kidney Foundation</a></td>
<td>Provides information for patients, medical professionals &amp; the public regarding Kidney Disease.</td>
</tr>
<tr>
<td>[United Network for Organ Sharing (UNOS)]</td>
<td>Provides information and data about transplants, living donation, the waiting list, and transplant centers.</td>
</tr>
<tr>
<td><a href="organdonor.gov">US Department of Health &amp; Human Services</a></td>
<td>Provides information about organ donation and transplantation.</td>
</tr>
<tr>
<td>[Organ Procurement &amp; Transplantation Network (OPTN)]</td>
<td>Contains all national data on the candidate waiting list, organ donation and matching, and transplantation. Provides Member Directory to allow patients to search for nearby transplant centers.</td>
</tr>
<tr>
<td><a href="livingdonorassistance.org">National Living Donor Assistance Center</a></td>
<td>Provides financial assistance with travel costs and expenses associated with living donation.</td>
</tr>
<tr>
<td><a href="americantransplantfoundation.org">American Transplant Foundation</a></td>
<td>Provides information, resources, and stories about kidney transplant. Perspectives are coming from medical professionals as we all as transplant patients and donors.</td>
</tr>
<tr>
<td><a href="lkdn.org">Living Kidney Donors Network</a></td>
<td>Promotes education to the general public about living kidney donation as well as provide specific information to patients so that they can effectively communicate their needs.</td>
</tr>
<tr>
<td><a href="kidneyregistry.org">National Kidney Registry</a></td>
<td>Uses advanced technology and large pools of donor/recipient pairs to find better matches through “paired exchange.”</td>
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Brainstorm Sheet / Opportunities

Where do you go? Who do you see there?

**Friends / Family**

1) ____________________
2) ____________________
3) ____________________
4) ____________________
5) ____________________
6) ____________________
7) ____________________

at Work?
at Church?
at Community Center?
within Hobby Groups?
at Grocery Store?
Letter Templates (for mail or email)

OVERVIEW:
This letter could come from a friend or family member of the person who is in need of a transplant.

The letter should include the following if possible:
1) Introduction of patient and Champion and why you are sending this letter.
2) Short medical history explaining why patient needs a kidney.
3) Explanation why Champion cannot be donor.
4) Request to spread the word.
5) Request for potential donors to get a blood test (mention that you are especially hopeful of finding a type O donor if patient is type O).
6) Contact info for the Transplant Program website, in order to make initial contact and to begin the living donor evaluation process.
7) Christiana Care Kidney Transplant Program will only evaluate two potential donors at a time. Thus, to reduce the chance that a strong candidate is kept waiting, you may want all potential donors to contact you or your Champion (not the transplant center) first, and pick the most determined potential donor to go through the evaluation first.
Sample Letters (for mail or email)

**EXAMPLE:**

Dear (Personalize letter if possible),

I am writing to you about my (i.e. friend, brother), Mike. It’s to let you know about his current health challenge, and how you can help. This is not an easy letter for me to write, but I know that without sending this, someone who might be interested in helping won’t have that opportunity.

Mike is a wonderful person. (You could talk about the work that Mike does, his family, the volunteer work he has done, his involvement with the community, anything that could connect him with other people.)

Mike suffers from kidney failure. (Give a brief history of Mike’s health challenges. Mention if Mike’s on dialysis, had a previous transplant, how long he’s been waiting, how many other people have tried to help etc. You could even include a picture of Mike that you think others would like to see. If Mike has made many positive lifestyle changes, mention them. If you are unable to donate, explain why.)

Explain that there is a long wait for a deceased donor and the benefits of receiving a kidney from a living donor. (The wait for a deceased donor is over 5 years and a kidney from a living donor lasts twice as long as one from a deceased donor).

If Mike isn’t on dialysis, talk about how difficult it is to have a normal life while being on kidney dialysis, if he is on dialysis, you could describe the routine.

Be as straight forward as possible, “**Mike needs a new kidney, and we hope you will consider being tested to be a donor.**”

I know this is a big request. But I make it on behalf of someone who devotes every day of his life to making a difference to his family and friends.

“**If you can help, please do. If you know anyone who might, please forward this on.”** Forwarding this to your family, friends, workplace, school, congregation, or any other communities you belong to would be most gratefully appreciated.

If you think you may be interested in helping Mike, you could get a blood test or donate blood to find out your blood type. (You can mention that you are especially hopeful of finding a type O donor, if patient is type O). Even if you are not an exact match then there is always the option of paired donation, which allows for ‘swapping’ kidneys with someone who does match. If you would like to learn more about living kidney donation, please feel free to call me at XXX-XXX-XXXX. I want to be as helpful as possible. You can also visit www.christianacare.org/kidneytransplant to learn more about living kidney donation. If you are interested in considering living kidney donation you can visit www.christianacare.org/kidneytransplant and click on the blue box “Interested in Living Donation?” to see if you could be able to start the living donor evaluation process. Thanks for your consideration.

Sincerely,

[Sign your name (Patient or Champion)]
Donor Request Cards

Front

Give the Gift of Life

Interested in kidney donation?

Go to www.christianacare.org/kidneytransplant
and click on the blue box “Interested in Living Donation?” to complete an online form to see if you qualify to be a donor.

302-623-3866

Kidney Recipient’s Name

Back

This gift would be for:

Kidney Transplant Program

Have a conversation that includes:

- your need for a transplant,
- your risk of death if you stay on dialysis, and
- the advantages of a living donor transplant.

Ask if the person would consider getting tested to be a living donor.

Give them a card. (1 of your 10)

Ask them to contact the CCHS Kidney Transplant Program.

Record the results on the follow-up form (see page 32) to review with the transplant team.
Getting the word out...
Facebook... promoting awareness

Share your story in a positive manner

or

related items to your page

No need to create a new Facebook page or account for this one purpose.

Use your own personal Facebook.
Facebook... schedule your posts

- **Week One** – Introducing your situation

  - Post 1 (*Tuesday*): Explain reason you’re on dialysis, and that you’re now in need of a transplant; preferably a Living Donor transplant.

  - Post 2 (*Saturday*): Explain the wait for a deceased donor kidney is up to 7 years; and risks of being on dialysis. Share with folks you’re hoping on a living donor transplant.

- **Week Two** – Share facts about Living Donation

  - Post 3 (*Tuesday*): List the top 7 myths and facts. (See Fact Sheet)

  - Post 4 (*Saturday*): Explain that a living donor kidney lasts twice as long and typically has much better outcomes than a deceased donor kidney. Let alone the wait time is less than 6-months vs. the many years on dialysis.

- **Week Three** – Share the Joys of Life... and Call to Action

  - Post 5 (*Saturday*): Share something positive and personal that you enjoy about life. And that you’re hoping with your kidney transplant, you’ll be able to improve your quality of life and enjoy this item again/more. **Ask people to consider getting tested!**

  - Post 6+... repeat (posts 1-5 again.)
Removing Obstacles

I’m afraid I won’t know what to say. I’m nervous.

Review: Brochure “How to Find a Living Donor”, and Practice in front of a Mirror, or with someone.

What if they ask questions that I don’t know how to answer?

Refer to the Living Donor Champion Playbook… as it can answer nearly any question.

I feel like I don’t know who to ask.

Complete the Brainstorm Worksheet (identifying people)

What if they say “no”?

Then ask if they would be willing to be another Donor Champion to spread the word about your story?

Ask them if they have registered to be an organ donor on their license, if not, encourage them to do so.

Ask them to consider directed donation.
### Who are your Opportunities?

- **Family?**
- **Friend?**
- **At Work?**
- **At Church?**
- **At Community Center?**
- **Within Hobby Groups?**
- **At Grocery Store?**

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Who are your Opportunities?


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## Potential donor follow-up

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<tr>
<th>Name of Potential Donor</th>
<th>Discussion Date</th>
<th>Follow-up Date</th>
<th>Comments</th>
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What questions do you have?

Questions to ask the Kidney Transplant team about this training?

1)

2)

3)
What concerns do you have?

Write down your comments here....

1) ________________________________

2) ________________________________

3) ________________________________