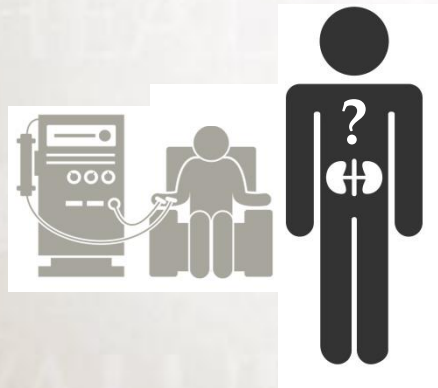


Living Donor Champion Training

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



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

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.

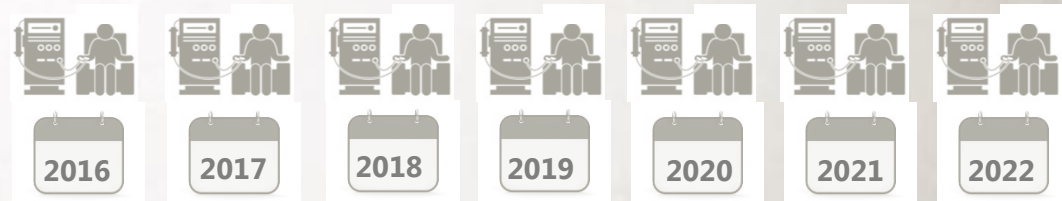
Take action with the Living Donor Champion Playbook.

So what's the problem?

Every year...

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

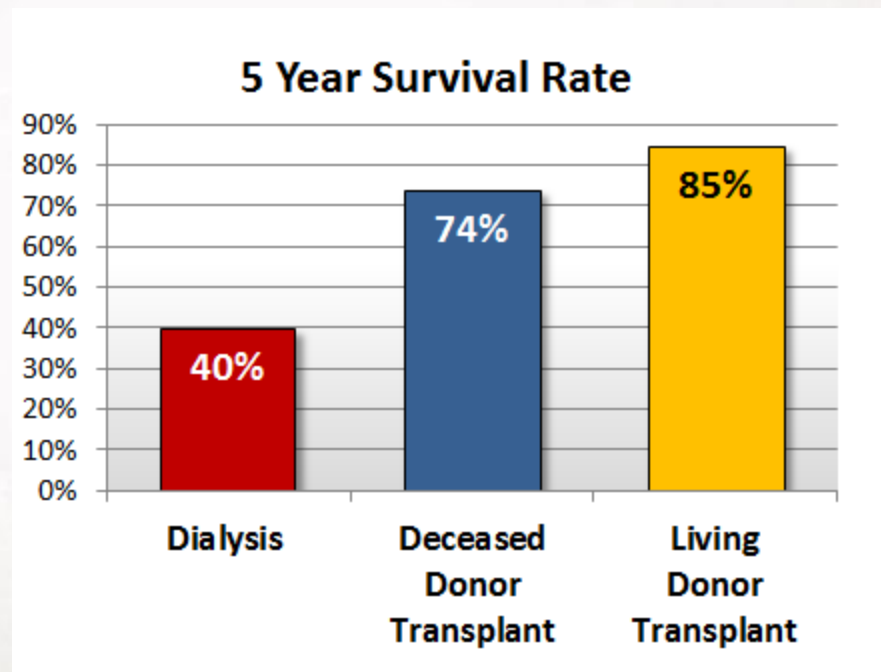
The wait time is
up to 7 years for
a deceased donor kidney



Patients will die while on dialysis

Statistics show...

6 out of 10 patients will die while on dialysis within 5 years.



Source: USRDS 2015; unadjusted & within 5 years, 40% survival on dialysis.

Two Options for Transplant

Deceased Donor



Living Donor



Source: Getty Images & <http://bangordailynews.com/2014/03/13/living/kidney-donor-from-veazie-recipient-from-caribou-form-special-bond/>

Benefits of Living Donor Transplants

**Living
Donor**

Deceased
Donor

Shorter wait times to transplant

6 months

vs.

up to 7 years

How long the kidney will last

20 years

vs.

8 years

Planning the surgery

Yes

vs.

No

* NOTE: Individual results may vary.

Source: USRDS 2015; unadjusted & within 5 years, 40% survival on dialysis.



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.

Living Donation is the Best Option

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

Fact: Kidney donors typically only have pain the first several days.

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

Fact: Kidney donors will be walking before discharge.

Living Donation is the Best Option

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   Direct conversations

 Letters and emails  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.

- Ask someone to be your champion, your recruiter.
(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.

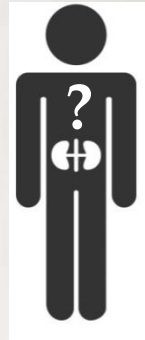
Roles & Responsibilities

Patient

- Takes responsibility for their health
- Coordinates with Living Donor Champion

Living Donor Champion

- Creates awareness for patient to get a Living Donor

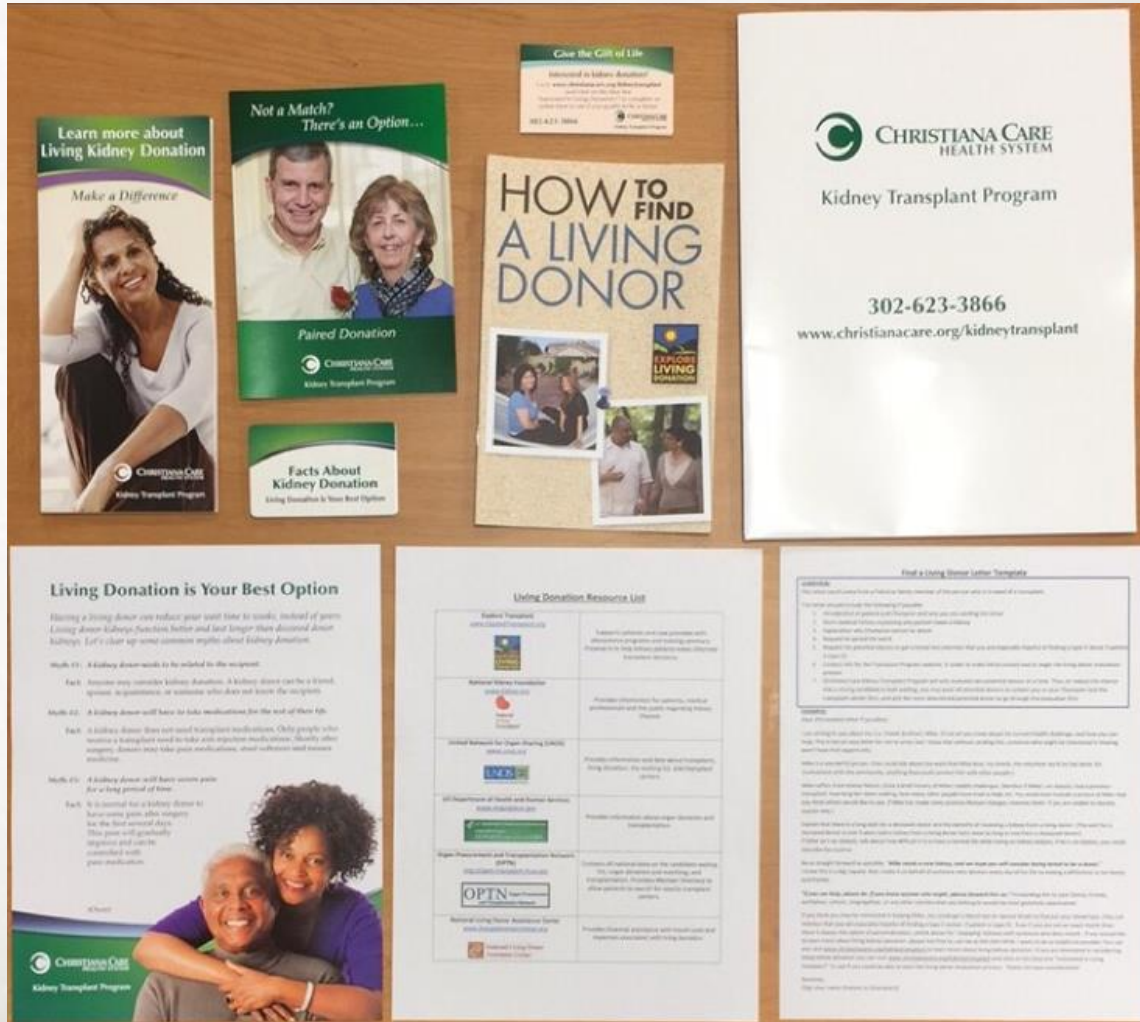


This training is your critical 1st step

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 brainstorming worksheet)

What are your next steps?

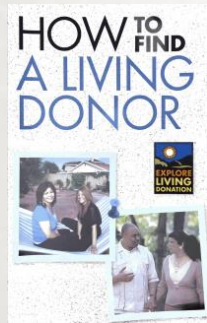
Brochures

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

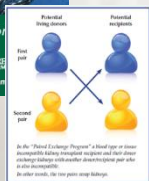


A booklet that provides ideas for recipients or Living Donor Champions to find a potential living donor.

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.”



Handout & expandable pocket card

Living Donation is your best option

(Myth & Fact Sheet):

A handout of common myths
and the 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.*

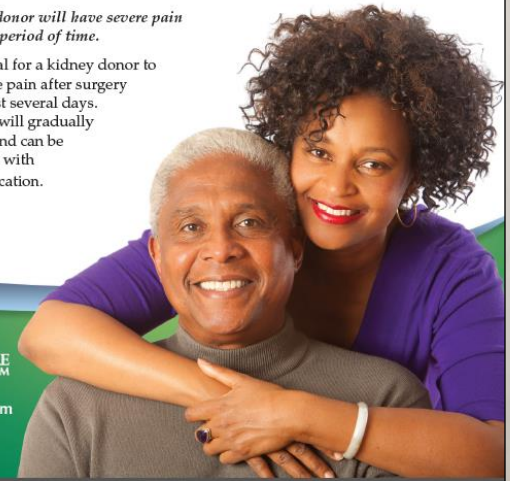
Fact: It is normal for a kidney donor to have some pain after surgery for the first several days. This pain will gradually improve and can be controlled with pain medication.

(Over)



CHRISTIANA CARE
HEALTH SYSTEM

Kidney Transplant Program



CHRISTIANA CARE
HEALTH SYSTEM

Online Resources List

Explore Transplant

www.ExploreTransplant.org



Supports patients and care providers with educational programs and training seminars. Purpose is to help kidney patients make informed transplant decisions.

National Kidney Foundation

www.kidney.org



Provides information for patients, medical professionals and the public regarding Kidney Disease.

United Network for Organ Sharing (UNOS)

www.unos.org



Provides information and data about transplants, living donation, the waiting list, and transplant centers.

US Department of Health and Human Services

www.organdonor.gov



Provides information about organ donation and transplantation.

Organ Procurement & Transplantation Network (OPTN)

<http://optn.transplant.hrsa.gov>



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.

National Living Donor Assistance Center

www.livingdonorassistance.org



Provides financial assistance with travel costs and expenses associated with living donation.

Online Resources List

American Transplant Foundation

www.americantransplantfoundation.org



Provides information, resources, and stories about kidney transplant. Perspectives are coming from medical professionals as well as transplant patients and donors.

Living Kidney Donors Network

www.lkdn.org



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.

National Kidney Registry

www.kidneyregistry.org



Uses advanced technology and large pools of donor/recipient pairs to find better matches through "paired exchange."

Alliance for Paired Kidney Donation

www.paireddonation.org



Provides a service that helps educate people about paired donation. Additionally, helps to connect people with others they know will be compatible.

Give a Kidney

www.giveakidney.org



Provides information about the benefits of becoming a kidney donor. This includes education about safety, the operation specifics, and the before/after process.

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,

Donor Request Cards

- 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.

Front



Give the Gift of Life

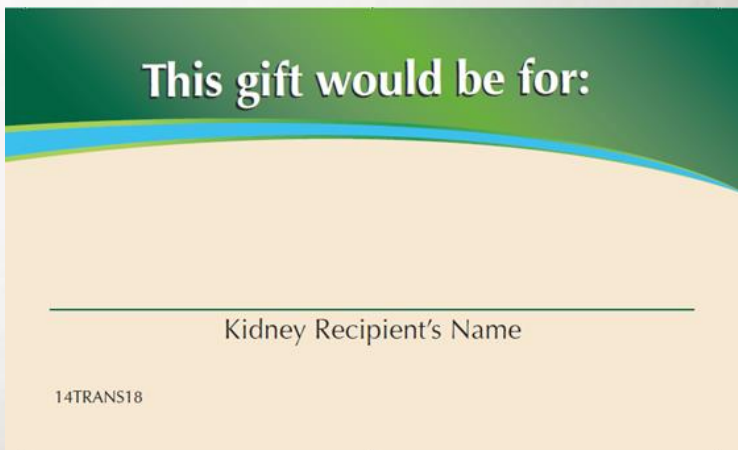
Interested in kidney donation?

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

 **CHRISTIANA CARE HEALTH SYSTEM**
Kidney Transplant Program

Back



This gift would be for:

Kidney Recipient's Name

14TRANS18

Anytime Access for Web Referrals

CHRISTIANA CARE HEALTH SYSTEM

Find a Job Find a Doctor Volunteer Press Room Contact **Make a Gift**

Search

Kidney Transplant Program

Life saving treatment close to home

Christiana Care offers the only adult kidney transplant program in Delaware. Our expert team of doctors and nurses works with you and your family to restore your health and transform your life.

With our [locations in northern and southern Delaware](#), you can be confident that your health care team is close at hand as you prepare for your surgery and to start your new life.

Call 302-623-3866 for more information, or [ask our Transplant Team](#) a question online

[Request an appointment](#) [Interested in Living Donation?](#)

About Us
[About our program](#)
[Meet the team](#)
[Patient stories](#)
[Refer a patient](#)
[Upcoming events](#)
[Locations](#)

About Kidney Transplants
[What can I expect?](#)
[Preparing for transplant](#)
[Types of transplants](#)
[Transplant FAQs](#)
[Learn more](#)

[Transplant evaluation](#)
[After surgery](#)
[Paired Exchange Program](#)
[Donation FAQs](#)

Getting the word out...



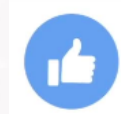
Getting the word out...



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 your 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.)

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) _____

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.

Removing Obstacles

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.

Potential donor follow-up list

	Name	Discussion Date	Follow-up Date
1)	_____	_____	_____
2)	_____	_____	_____
3)	_____	_____	_____
4)	_____	_____	_____
5)	_____	_____	_____
6)	_____	_____	_____
7)	_____	_____	_____
8)	_____	_____	_____
9)	_____	_____	_____
10)	_____	_____	_____

Who are your Opportunities?

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

- 1) _____
- 2) _____
- 3) _____
- 4) _____
- 5) _____
- 6) _____

- 1) _____
- 2) _____
- 3) _____
- 4) _____
- 5) _____
- 6) _____

Who are your Opportunities?

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

- 1) _____
- 2) _____
- 3) _____
- 4) _____
- 5) _____
- 6) _____

- 1) _____
- 2) _____
- 3) _____
- 4) _____
- 5) _____
- 6) _____