

# Using Social Media to Look for a Living Kidney Donor

Some people who are waiting for a kidney transplant decide to use social media sites such as Facebook, Twitter, Instagram and others to post about their kidney disease and to look for a living kidney donor. Using social media lets you share your story quickly and simply, and lets you reach a large number of people who might consider live kidney donation for you.

Please think about the pros and cons of using social media to find a living donor **before** posting online. We ask that you consider the information in this handout to help you decide if it is right for you.



## Should I Use Social Media to Find a Donor?

### Benefits of Using Social Media

- Lets many people know about your kidney disease and need for a transplant.
- Widens your search for a living donor; you may reach many people, including some you don't know.
- Speeds up your search; you can message friends and followers quickly.
- Social media may be more comfortable for you than a face to face conversation.
- Your posting may lead to a wider support network in general.

### Drawbacks of Using Social Media

- Once you post personal information online, it is out of your control. Posts can be shared or your information can be copied and pasted to other sites or pages.
- You may be disappointed if you do not get the response you are hoping for.
- You may be victimized by exposing personal information to people who may want to take advantage of you and your situation.
- You may be disappointed if possible donors don't go through with the full donor evaluation, which can be very hard on you and your loved ones.
- Large numbers of possible donors may contact the donor coordinators, and it takes time to review each donor – this may delay the evaluation of any one potential donor.

## If You Decide to Use Social Media

If you've considered the potential benefits and drawbacks of using social media to help you in your search and decided that it is right for you, **please talk to your transplant coordinator and/or transplant social worker BEFORE posting.** They can look over your post and help make sure you're including accurate information. Letting them know ahead of time about your plan to post can also help the live donor team prepare for the possibility of a larger number of inquiries and hopefully make the process more efficient for everyone.

## When Should I Post Something?

Please check with your transplant team about appropriate time to reach out to potential living donors.

## What Should I Include?

Deciding what information to include about yourself, your health, transplant and living donation can be hard!

We have developed some general recommendations to consider including when using social media to find a living donor:

- Share your story of kidney disease and how it has impacted you and/or your loved ones.
- Provide some basic information about transplant (i.e. how long the average wait is, benefits of live donor transplant).
- Provide some basic information about how to become living kidney donor – you can review the basic criteria at [www.bidmc.org/kidneydonor](http://www.bidmc.org/kidneydonor)
- Include a statement that the donor evaluation team is a separate team from your own and it is a confidential process.
- Please remember to include link to the BIDMC Information for Living Kidney Donors webpage: [www.bidmc.org/kidneydonor](http://www.bidmc.org/kidneydonor) and share that the best way to start the process is to complete the online intake form on this page.
- Actively maintain your page with posts and updates to let people know how you are doing and keep them engaged.
- Create a group page if you don't want to use your personal page for any reason.

## Is There Anything I Should Avoid Posting?

You are in control of how much or how little you share in your initial post and it's important to be thoughtful about what you put out there. If someone plans to post on social media on your behalf, please review with them what is and is not ok with you to post.

Some things to consider avoiding when using social media include:

- Personal phone numbers, addresses and emails
- Any health information that you might feel is sensitive and don't want shared with a wide network of people
- Remember that it is illegal to give money or any other item of value in exchange for a donated organ

## Example Post

You can modify it to include your personal experience:

*"Hi there! This is a difficult post to write but I want you all to know what is going on with me. You might already know that I have kidney disease. Well, I just found out that my best treatment option is kidney transplant. This was hard to hear but I am determined to get through this. One of the things the doctor talked about was living kidney donation as an option to get a transplant sooner and avoid dialysis. The wait for a deceased donor transplant can be five years or more with over 90,000 people on the list! The doctor also told us that kidneys from living donors can last longer and function better than kidneys from a deceased donor.*

*I know it's a lot to ask but would anyone be interested in learning more about being a living donor? If you are in good health, you might be able to donate to me. Living donors get a careful and thorough evaluation with a separate team of doctors, nurses and other healthcare professionals to ensure that living donation is as safe as possible for them. If your blood type doesn't match mine, we could be entered into a kidney swap (for more information, see <https://unos.org/donation/kidney-paired-donation/>)*

*Please send me a private message if you would like to talk more or would be interested in helping by considering donation or spreading the word about my need for a kidney transplant. You can also visit the Transplant Institute at BIDMC's webpage to learn more about living donation <http://www.bidmc.org/kidneydonor> or to confidentially complete the online intake form to be considered for living kidney donation. Thank you!"*

**KEEP IN MIND** that while social media can be an effective way to get the word out to people about your illness and search for a living donor, it is not the only tool you have. Think about your social networks and how you're comfortable reaching out to people.

Additional ways to reach people could include:

- Send an email or even a "snail mail"
- Share information through word of mouth at social gatherings
- Host an informational gathering of close friends/family at your home or another place you're comfortable
- Through your place of worship with a prayer request or posting in a bulletin/newsletter
- Ask someone to be a "donor champion" – someone who can help spread the message for you