

Living Organ Donation, Public Appeals & Social Media

A Resource for Patients and Families



Introduction

Social media campaigns have become increasingly common within the transplant community. For those in search of a living organ donor, social media offers an opportunity to quickly share your story publicly or with a large group of people in your network and beyond, with little to no financial cost.

This document will:

- ▶ Outline social media considerations.
- ▶ Answer frequently asked questions about using social media to find a living donor.
- ▶ Walk you through best practices for your social media campaign.
- ▶ Provide digital resources.

What is Social Media?

Simply put, social media is any website, online platform, or application that allows for online community building and social interaction. For example, Facebook, Instagram, Twitter, Youtube, personal blogs, and email help people share ideas, information, and experiences in the form of videos, text, photography, and more. It can help you stay in touch with family and friends or connect you to complete strangers who share a common interest or goal.

While social media can seem intimidating, it is important to remember that you have control over what you share and with whom. Most social media allows you to post privately (to a select group of people approved by you) or publicly (to anyone who comes across your post). Social media is an excellent way to get someone's attention and direct them to a more complete source of information such as a website.

How Can Social Media Help Me Find a Living Donor?

Social media can help you share your story and expand your circle of potential donors. Most transplant candidates are uncomfortable with the idea of directly asking someone to be their living donor. We recommend that you keep those close to you up to date on your health, including the fact that your doctor has recommended transplant. If you provide people with information, someone may come forward to be your living donor without you having to explicitly ask.

Not all social media has to be public. You can start by communicating to those closest to you, your “inner circle” of family and friends. If you choose, you can expand your circle to colleagues, faith groups, book clubs, and beyond. Be mindful that while public social media campaigns may help you find an unrelated or anonymous donor, most organ donors are initially motivated by donating to someone they know. Start by sharing your story with your immediate circle, and provide updates as you learn more, or as your condition changes.

Explore Living Donation

Dr. Amy Waterman has developed www.explorelivingdonation.com, a website that profiles real people – living donors, recipients, family members – and their living kidney donation and transplantation stories. These may be helpful as you begin to think about the path ahead.

Discover the Canadian Living Donor Online Community

Social media is a great place to connect with the living donor and transplant community. Share your story and ask for help finding your living donor. Or find a living donor champion – a family member, friend or colleague - to do this for you.

FINDING A LIVING DONOR

WHO CAN BE A LIVING DONOR?

Anyone who meets the screening criteria can be a living donor. Donors do not need to be a blood relative, the same age, race, or gender as the recipient. Donors can be anyone.

WHO IS ELIGIBLE?

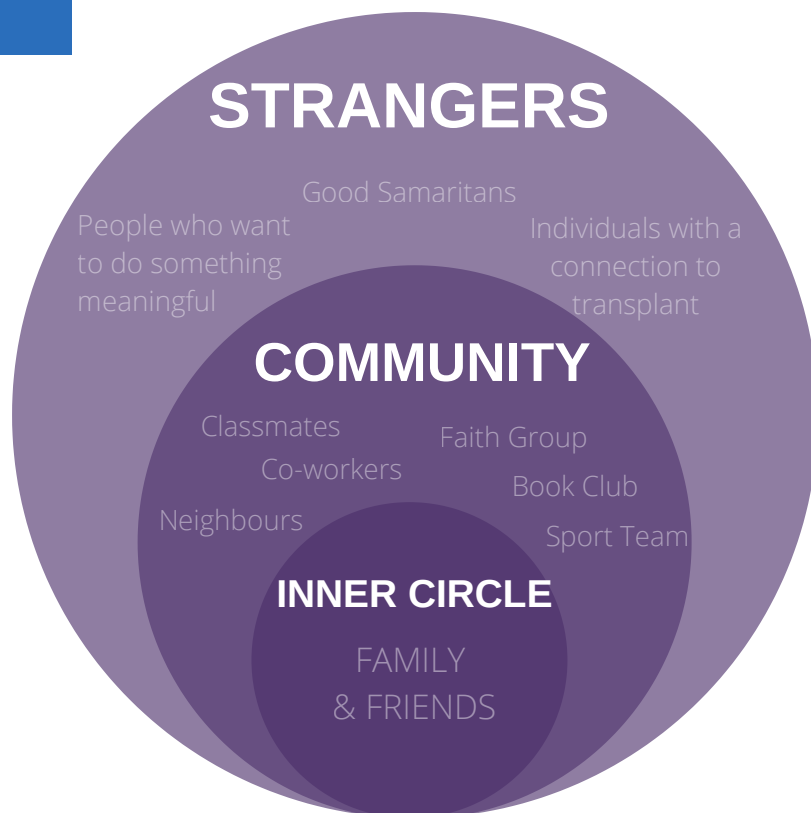
- Age 16-60 (liver donor) or 18+ (kidney donor)
- Healthy weight for height - or have a body mass index under 35
- Anyone in good overall health (no cancer, diabetes, etc.)
- Compatible blood type with the recipient (if you are not compatible with a potential donor, there are other options - contact us for more information)

By sharing information about your circumstance, someone may come forward without you having to ask.

You might already know your living donor.

HOW DO I START?

- Start by updating your family and friends (your "inner circle").
- Tell them that your doctor has recommended transplant.
- If you're comfortable, widen your circle to your neighbours, community groups, coworkers, and beyond.



[Visit transplant.bc.ca](http://transplant.bc.ca) to get tips on how to start the conversation about living donation.

What is a Living Donor Champion?

Not everyone will be a living donor, but everyone could be a champion for your cause. A living donor champion advocates for and speaks out about living donation. They encourage and support you as you go through the steps toward transplant and act on your behalf in the search for a living donor.

Living donor champions help by:

- Alleviating pressure on your efforts to find a living donor.
- Starting the conversation about living donation.
- Spreading awareness about living donation.
- Providing you emotional support as you go through the steps toward transplant.

The Centre for Living Organ Donation offers a free Living Donor Champion Webinar every month. Visit GiveLifeUHN.eventbrite.com to register.

Getting the Conversation Started

Here's an example of a message your champion might send out at your work place.

Hi all,

As you are aware, Mary Smith has been off for some time now. She has given me permission to let you all know how she is doing. Many of you may not know that Mary has polycystic kidney disease, an illness that eventually results in kidney failure.

This has recently happened to Mary and she has started dialysis. As this disease runs in families, many of Mary's relatives find themselves in a similar situation. Nonetheless, she is hopeful about eventually finding a living kidney donor for a transplant.

Currently, she is on the lengthy waiting list for a kidney from a deceased donor. I am sure we all wish Mary our best for better health in her future.

Source: The Kidney Foundation of Canada

For more templates and examples visit www.facebook.com/givelifeUHN

Social Media Considerations

While many individuals in need of a transplant have been helped through social media campaigns, there are some things to consider before you make the decision to share information on a public platform.

ELIGIBILITY

Before asking someone to apply to be your living donor through the UHN Transplant Program, please confirm you are eligible for a living donor transplant and have been accepted as a patient at UHN.

Sometimes referrals take time, particularly if you are receiving care outside of Ontario or on the deceased donor wait list at another hospital. We will not begin assessing living donor candidates until we have received your referral and you have been cleared for transplant.

You will receive a phone call and letter from UHN confirming you have been cleared for transplant. If you have not received clearance for transplant, UHN cannot assess potential living donors for you.

PRIVACY

Sharing your story on social media involves disclosing personal health information. It may also involve details about your family or work life, and other sensitive information. This is your information to share but know that once it is made public you have no control over how it will be shared or used.

Be considerate of others who are involved in your story and their privacy. If you take pictures or recordings for your campaign, get permission from those individuals whose pictures, videos, or voices you capture. Your family and friends, as well as hospital staff and other patients, have a right to privacy.

MANAGING YOUR CAMPAIGN

Your campaign may generate a lot of interest. Depending on where and how you share your information, this interest could mean an influx of direct messages, emails, or phone calls. It is important to anticipate this reaction and to plan for it. This may involve setting up a new email account for your campaign and asking friends or family to help respond to messages and calls.

Deciding to become a living organ donor is a big decision and there are risks. Develop a list of common questions about your condition and living donation so you are prepared. Please ensure that the information you are sharing is factually correct. You can fact check anything you will be sharing publicly with the Centre for Living Organ Donation at UHN or simply link to our website www.livingorgandonation.ca.

You can find a bank of educational material on our Facebook page, facebook.com/GiveLifeUHN. Please feel free to use this content for your campaign.

Never answer a question if you are unsure of the answer. Always direct potential living donors to the Centre for Living Organ Donation for more information. Our Outreach Coordinator, Heather Lannon can answer these questions or find the answer for you.

Heather Lannon
Outreach Coordinator
The Centre for Living Organ Donation at UHN
livingorgandonation@uhn.ca

If your story attracts the attention of the media, contact:

Courtney Mahrt
Communications Coordinator
The Centre for Living Organ Donation at UHN
livingorgandonation@uhn.ca

We can help to facilitate your interactions with the media, as well as the media's interaction with and access to the hospital. No information will be given to any member of the media about an individual patient without the express consent of that patient or their Substitute Decision Maker (SDM).

PROTECTING ANONYMITY

Ontario protects the identity of anonymous (non-directed) living donors, as well as the identity of deceased donors. If you receive a donation from an anonymous living donor or a deceased donor please refrain from sharing the specific time and date of your surgery to respect the privacy of those involved.

FUNDRAISING

From time to time, patients use the media and social media to raise funds to support their transplant or living donation expenses, particularly if they live outside of the Greater Toronto Area and require the specialized care only UHN can provide. UHN cannot take part in fundraising for individual patients. We do provide information on sources of funding available in different provinces, expense reimbursement, and other supports available for living organ donors, including those who live outside of Canada.

PUBLIC RESPONSE

You cannot control how people will interpret your campaign. Be prepared if the response to your appeal is not entirely positive - some people see public campaigns as “jumping the line,” even though this is not the case. By finding a living donor and having a living donor transplant, you do not take an organ from the deceased donor wait list pool.

Be patient if the response to your appeal is slow or if only one or two people respond. This is not a reflection of your worth as a person. Some campaigns generate a lot of inquiries and press coverage but may not lead to a lot of donor applicants who complete the assessment process. Other campaigns are slow and steady - and successful - because they communicate honestly and living donor candidates commit to seeing the process through.

At the end of the day, it only takes one healthy person to be a match. **Stay strong!**



From a young age, Claudia suffered from Polycystic Kidney Disease (PKD), a genetic disorder that eventually shut down her kidneys. After her doctor explained that her best chance for survival was a kidney transplant, Claudia shared her health status with her church. Her youth minister made a social media video that was shared across the globe. Julia, a Toronto resident, saw the video and stepped forward. On May 22, 2018 Julia gave Claudia a second chance at life.

Frequently Asked Questions

Can UHN help me start a social media campaign?

Unfortunately, no. UHN – including the Transplant Program, the Centre for Living Organ Donation, and the Toronto General and Western Hospital Foundation – can provide general information on living donation, the donor assessment process, and how to become an effective donor champion but we cannot help you start a social media campaign or find a living donor. We cannot advocate on behalf of any one patient. We simply do not have the resources to advocate for all our patients equally.

How do I start a social media campaign?

Starting a social media campaign will require you or your living donor champion to have a social media account. If you are new to the world of social media, you might consider a Facebook account to start. You can share information regarding your living donor appeal on your personal Facebook account or start a Facebook Group or Page.

A Group is designed to bring people with a common interest together. Everyone in the group can share content, express opinions, and ideas. You can make your group public or private, depending on what settings you choose.

A Page is used to create an authentic and public presence on Facebook. Pages are public by default. People can follow your page and will receive updates when you post to that Page. You can decide if you would like to allow others to post to your Page. They will be allowed to comment on posts by default.

To create a Group or Page, click on Create at the top right of the Facebook homepage. Select Group or Page, depending on your preference.

Finally, discover the online living donor and transplant community by joining Groups. This is where you will find people who have created other appeals for living donors, as well as transplant candidates, recipients, past donors, their family and friends. In our experience, most are happy to share their lived experience and offer advice.

Will you test everyone who applies to be my donor?

We assess one donor per recipient at a time. If several donors come forward at the same time, the donor who is most likely to be your match will be tested first. If this donor is deemed unsuitable by the living donor team, we will test another donor.

For privacy reasons, we cannot provide you with any information about your potential donors, including how many people have submitted applications.

If I have a social media campaign, do my potential donors get priority in the assessment process?

At UHN, we treat all recipients and their potential living donors equally. Launching a social media campaign will not give one recipient priority over another.

Can I start a fundraising campaign to cover my expenses and help my living donor?

Fundraising is entirely up to you. UHN cannot take part in fundraising for individual patients. If you choose to start fundraising for yourself, be transparent about where the money is going. Ex. *I am raising money to cover the cost of my family member's hotel room so they can stay close to the hospital.*

If you would like to start fundraising for your donor, keep in mind that **it is illegal to pay organ donors in Canada**. You can raise money to reimburse your donor for out-of-pocket expenses - such as air fare, travel accommodations, etc. - but you cannot pay them for their donation. Trillium Gift of Life Network also provides a Program from Reimbursing Expenses of Living Organ Donors (PRELOD). There is a monthly webinar about PRELOD available at GiveLifeUHN.eventbrite.com.

Have a question that's not answered here?
Send it to us at livingorgandonation@uhn.ca

Best Practices For Your Living Donor Appeal

Whether you are searching for your own living donor or your living donor champion is searching for you, here is some information we would recommend sharing for an effective campaign.

BEFORE YOU BEGIN

First and foremost, ensure that you are confirmed as eligible for a living donor transplant and are on the wait list. You will receive a phone call and letter from UHN confirming that you are on the list. For someone to apply to be your living donor through the UHN Transplant Program, you must be eligible for living donor transplant and a patient at UHN.

If you are receiving care in the community or outside of Ontario please confirm your referral has been received by UHN before starting your social media campaign.

WHAT TO SHARE

Include a brief summary of your story. Describe what life was like before you got sick, why you need a living donor, what blood types are compatible with yours*, and any other relevant information or photos you are comfortable sharing. Put this in the About section of your personal page, Group, or Page, so that anyone arriving for the first time can find it.

In the About section, you should also include the general eligibility for living donors:

- Age 16 – 60 (living liver donors) or 18+ (living kidney donors)
- Blood type(s) that are compatible with yours*
- Healthy weight for height or body mass index under 35
- Include the link to the UHN Health History Form. Filling out and submitting this form to the Transplant Program is the first step to becoming a living donor. You can find the link at uhntransplant.ca.

*If your potential donor has a blood type that is incompatible with yours, there may be other options available.

Email livingorgandonation@uhn.ca to learn more.

WHAT NOT TO SHARE

Avoid sharing sensitive personal information, particularly if you are sharing beyond your inner circle. Avoid posting personal phone numbers, email addresses, residential addresses, family or personal information, and photos you do not want shared publicly. If you are sharing information, photos, or recordings of other individuals, you must have their express consent to do so.

Do not share contact information for the transplant team or the living donor office. This will cause stress on these resources and could result in a delay in donors being assessed.

Do not provide misleading information about your situation or living organ donation. Becoming a living donor is a big decision and those considering it deserve to have the correct information.

Do not offer incentives, rewards, or compensation for organ donation – this is illegal. Donors are screened for coercion.

Do not provide medical advice. If a potential donor asks about details regarding surgery, medication, recovery, etc. tell them to contact the Centre for Living Organ Donation for more information.

REMEMBER

The first step is to fill out the **Health History Form** available on the Living Donor Program site. After the completed form has been submitted, the Living Donor Office will call to confirm that the application has been received.

uhntransplant.ca

Online Resources

LIVER

UHN Living Liver Donor Program
UHN Liver Transplant Program
UHN Living Liver Donor Manual
Liver Health, The Canadian Liver Foundation
Liver Diseases, The Canadian Liver Foundation

KIDNEY

UHN Living Kidney Donor Program
UHN Kidney Transplant Program
UHN Living Kidney Donor Manual
Kidney Paired Donation Program, Canadian Blood Services

GENERAL HEALTH

Do you know your blood type, Canadian Blood Services
BMI Calculator, Mayo Clinic

LIVING DONOR AND TRANSPLANT RELATED FACEBOOK GROUPS

Canadian Transplant Association
Organ Transplant – Living Donor Awareness Group
Organ Transplant Recipients and Living Donors in Canada
Canadian Liver Foundation
Kidney Health Education & Research Group
National Kidney Foundation

Please note: we cannot guarantee the accuracy of information published on sites external to UHN. If you would like to verify any information, please contact:

The Centre for Living Organ Donation at UHN
livingorgandonation@uhn.ca
416-340-5400
www.livingorgandonation.ca



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