

# Guidance for Transplant Hospitals on Transplant Candidate Use of Social Media to Find Living Donors

## Purpose of this Guidance

Transplant hospitals face challenges in how best to guide patients on the appropriate use of social media with concerns about how best to assess the motivations and relationships of living donors identified through social media campaigns. It can be challenging to manage increasingly popular social media campaigns with existing resources. Additionally, some hospitals worry about furthering disparities by encouraging social media use when not all patients have equal access to the requisite resources. This paper seeks to uniformly guide all transplant hospitals on the safe and effective use of social media campaigns with the goal of increasing the overall number of transplants.

## Background

Living donor transplantation can offer patients with end-stage kidney or liver disease increased access to organ transplant and better outcomes than deceased donor transplantation.<sup>1,2,3</sup> A barrier to living donor transplantation is the ability of patients to identify possible donors. Challenges in identifying a living donor often stem from inadequate knowledge of the benefits, risks, and opportunities of living organ donation and transplantation across a patient's family, social networks, and the community in general. Patient and family education followed by messaging to those networks increases the likelihood of finding a living donor. Historically, patients communicated their need for a living donor through personal connections, announcements at work or church, billboards, flyers, signs on cars, newspaper ads, etc. In recent years, social media platforms have emerged as a potentially far-reaching and effective way to share information about a patient's need for a living organ donor.

While the use of social media to message a patient's need for a living donor can be an effective communication tool to reach people who may be interested in donating, it requires attention to online privacy, safety, and legal requirements associated with living donation. It also requires serious effort to minimize disparities and disadvantages to those with low access to or knowledge about the effective use of this communication technology. Transplant hospitals face challenges in guiding patients on the appropriate use of social media and how to effectively evaluate the sudden influx of potential living donors that volunteer due to an effective social media campaign.

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<sup>1</sup> U. S. Renal Data System. USRDS 2015 Annual Data Report: End-stage Renal Disease (ESRD) in the United States. Ch 7: Transplantation. [https://www.usrds.org/2016/view/v2\\_07.aspx](https://www.usrds.org/2016/view/v2_07.aspx) (Accessed: December 10, 2019).

<sup>2</sup> Humar A, Ganesh S, Jorgensen D, Tevar A, Ganoza A, Molinari, M, Hughes C. Adult Living Donor Versus Deceased Donor Liver Transplant (LDLT Versus DDLT) at a Single Center. *Annals of Surgery*: September 2019 - Volume 270 - Issue 3 - p 444–451. doi: 10.1097/SLA.0000000000003463 [https://cdn.journals.lww.com/annalsofsurgery/Abstract/2019/09000/Adult\\_Living\\_Donor\\_Versus\\_Deceased\\_Donor\\_Liver.6.aspx](https://cdn.journals.lww.com/annalsofsurgery/Abstract/2019/09000/Adult_Living_Donor_Versus_Deceased_Donor_Liver.6.aspx) (accessed December 11, 2019).

<sup>3</sup> Hoehn RS, Wilson GC, Wima K, Hohmann S, Midura E, Woodle E, Abbott D, Singhal A, Shah S. Comparing living donor and deceased donor liver transplantation: A matched national analysis from 2007 to 2012. *Liver Transpl*, 20: 1347-1355. doi:10.1002/lt.23956. <https://aasldpubs.onlinelibrary.wiley.com/action/showCitFormats?doi=10.1002%2F1t.23956> (accessed December 11, 2019).

## What Is Social Media?

Social media describes internet-based applications that allow people to interact with each other and to share information at the user's discretion. Some common types of social media interaction include:

- Sharing links to content produced by third parties (i.e., articles)
- Posting updates to one's profile, such as current activities, interests, and location
- Sharing photos and videos
- Commenting on or sharing others' photos, posts, updates, videos and links<sup>4</sup>

Social media commonly refers to platforms such as Facebook, Twitter, Instagram, YouTube, Reddit, LinkedIn, Tumblr, Blogger, etc.

## Transplant Hospital Social Media Survey

The OPTN Living Donor Committee (the Committee) commissioned a survey to inform this paper. Its purpose was to identify effective practices for transplant hospitals to advise patients about the safe and effective use of social media and efficiently managing the administrative challenges that arise when patient's social media campaigns generate a substantial number of potential living donors. The full report of the survey results is available upon request through an OPTN Data Request.<sup>5</sup>

## Challenges

Patients attempting to use social media to obtain a living donor face multiple challenges. The survey revealed that 60 percent of respondents reported hearing from their patients on difficulties such as limited knowledge of social media, privacy concerns, and limited access to technology.<sup>6</sup> Approximately 40 percent of survey respondents reported experiencing challenges within their transplant program related to social media. The principal challenge experienced by survey respondents was the prevalence of unprepared or uneducated potential living donors. Other challenges included questionable or inappropriate donor and recipient behavior, an influx of interested donors that is hard to process in a timely way, privacy issues, misinformation, and unrealistic donor and patient expectations. Specifically, living donors emerging from social media campaigns were frequently found to be unprepared or uneducated, have questionable or inappropriate expectations from the recipient or the transplant center, or created logistical constraints diminishing the transplant center process efficiency (i.e. sudden influx of potential living donors who rapidly exhaust existing transplant hospital resources).

## Social Media is Unregulated and Unmonitored

Information disseminated through social media is unregulated and unmonitored. Thus, patients campaigning in social media are at risk of misinforming or misrepresenting situations or events to their audience. Further, the audience reached through a social media post is likely to be unknown and untraceable, deepening the consequences of misinformation and making a correction difficult or impossible.

As a result, when a patient misinforms the audience about living donation, the burden of re-educating potential living donors falls upon transplant hospitals. Problems frequently include inaccurate donor understanding of risks or perceived financial incentives or exchange for assets. In the survey, the most

<sup>4</sup> "Social Media." Techopedia.com. <https://www.techopedia.com/definition/4837/social-media> (accessed November 26, 2019).

<sup>5</sup> OPTN Data Request. <https://optn.transplant.hrsa.gov/data/request-data/>

<sup>6</sup> OPTN Descriptive Data Request. "Living Donor Committee Social Media Survey Results." Prepared for Living Donor Committee Meeting, October 4, 2019.

common administrative challenge related to social media was unprepared or uneducated potential living donors. Other challenges related to the unregulated or unmonitored nature of social media included questionable or inappropriate donor and recipient behavior, an influx of interested donors that is hard to handle in a timely way, misinformation, and unrealistic donor and patient expectations.<sup>7</sup>

Transplant or living donation-related application developers and vendors, some of whom have a cost for service, are also unregulated. Patient use of commercial applications may not necessarily relieve a transplant hospital of the need to manage misinformed potential donors. This can further the challenge transplant programs face with uneducated or misinformed potential living donors.

## Patient Privacy Implications

In general, any internet activity directly risks one's privacy, with implications ranging from the potential disclosure of personal information to identity theft. Social media can threaten patients' privacy in a more profound way. Because the success of a patient's campaign depends on the empathy generated within their audience, patients must differentiate their story and needs from others. Thus, it is not uncommon for living donor social media campaigns to be heavily populated with personal, (i.e. phone numbers, addresses and emails), demographic, genealogical and health-specific information.<sup>8</sup> Such information can result in a range of unwanted solicitation or contacts in real time, or in a delayed fashion after being indexed in data warehouses.<sup>9</sup>

Patients face increased risks when they share personal health information on social media in an effort to find a living donor. Some of the risks include:

- Potential disclosure of protected health information (PHI).
- Insurance fraud and medical identity theft, since social media platforms are not bound by HIPAA.<sup>10</sup>
  - Medical identity theft can harm a patient when a scammer puts his or her own medical history into a patient chart.
  - Medical identity theft can lead to delayed or incorrect treatment or refusal of benefits and services when annual maximums are fraudulently exhausted.<sup>11</sup>
  - On average, patients who experienced medical identity fraud spent \$13,500 in legal and medical fees to correct the problem.<sup>12</sup>
- Social consequences from stigma associated with illness.
- Employment and future employment consequences:
  - In 2017, 70 percent of employers reviewed social media profiles to screen potential job candidates. This is an increase from 11 percent in 2006.<sup>13</sup>
  - Use of data by insurance companies to predict the health insurance costs of potential

<sup>7</sup> OPTN Descriptive Data Request. "Living Donor Committee Social Media Survey Results." Prepared for Living Donor Committee Meeting, October 4, 2019.

<sup>8</sup> Henderson, ML, Clayville, KA, Fisher, JS, Kuntz, KK, Mysel, H, Purnell, TS, Schaffer, RL, Sherman, LA, Willock, EP, & Gordon, EJ. (2017). Social media and organ donation: Ethically navigating the next frontier. *AJT* 17:2803-2809. DOI: 10.1111/ajt.14444

<sup>9</sup> "5 patient-centered social media risks." *Healthcare IT News*. <https://www.healthcareitnews.com/news/5-patient-centered-social-media-risks> (accessed November 26, 2019).

<sup>10</sup> "How Much Health Information Should You Share on Social Media?" *NextAvenue*. <https://www.nextavenue.org/how-much-health-information-should-you-share-on-social-media/> (accessed November 26, 2019).

<sup>11</sup> "How to delete yourself from the Internet (2018 guide)." *Reputation Defender*. <https://www.reputationdefender.com/blog/privacy/privacy-risks-sharing-health-info-online> (accessed November 26, 2019).

<sup>12</sup> "Medical Identity Theft." *AARP*. <https://www.aarp.org/money/scams-fraud/info-2019/medical-identity-theft.html> (accessed November 26, 2019.)

<sup>13</sup> "Number of Employers Using Social Media to Screen Candidates at All-Time High, Finds Latest CareerBuilder Study." *CareerBuilder*. <http://press.careerbuilder.com/2017-06-15-Number-of-Employers-Using-Social-Media-to-Screen-Candidates-at-All-Time-High-Finds-Latest-CareerBuilder-Study> (accessed December 3, 2019).

clients. Information related to diagnosis and treatment can inadvertently affect the type and cost of medical coverage available in the future.<sup>14</sup>

- Increase in unsolicited marketing of medical services, products or trial participation based on data collected that includes disease disclosure.<sup>15</sup> Data repositories have access to billions of online records and use the data to create profiles that are sold for profit.

Approximately 44 percent of survey respondents reported that their transplant hospitals do not set expectations differently for patients using social media. Of those respondents that do, counseling about potential privacy concerns was a chief area of caution. Of those transplant hospitals to whom patients have shared challenges about the use of social media, 42 percent reported that patients shared privacy concerns.

## Psychological Distress of Patients

Patients who use social media to identify a living donor may have greater psychosocial distress compared to those who use other methods. Committee members identified examples of psychosocial stress including:

- Insecurity about using social media and the ability to execute an effective social media campaign.
- Vulnerability due to loss of privacy and public dissemination of information about disease and needs.
- Worry about whether the patient’s story is sufficiently appealing to invoke a sense of empathy.
- Uncertainty about potential living donors’ motivations and expectations.
- Disappointment or sense of abandonment if no donor steps forward at all, if there is no follow through after initial expressions of interest, or if potential living donors are deemed unsuitable to donate. Potential living donors identified through social media campaigns may screen out before evaluation at higher rates than potential living donors who emerge through other means.<sup>16</sup>
- Perpetual indebtedness to people who step forward to donate.
- Guilt about “bypassing” other patients waiting to be transplanted.

## Disparities in Patient Access to and Knowledge of Social Media Tools

Substantial differences in access, knowledge, and effective use of social media platforms to identify a living donor exist across patient populations and geographic areas. This lack of agency constitutes a primary barrier to a successful social media living donor campaign and can exacerbate existing disparities in access to transplant. The survey supports this, citing limited knowledge of social media and limited access to technology as two of the top concerns shared by patients regarding use of social media campaigns.

Many of the following disparities in access to social media do not have ready solutions:

- Access to technology, including but not limited to internet access and reliability, data plans, computers, and smart phones.
- Ability to afford technology.
- Computer proficiency.
- Geographic proximity or adequate public transportation to publicly available resources such as a

<sup>14</sup> “How to delete yourself from the Internet (2018 guide).” Reputation Defender. <https://www.reputationdefender.com/blog/privacy/privacy-risks-sharing-health-info-online> (accessed November 26, 2019).

<sup>15</sup> Ibid.

<sup>16</sup> Suzanne McGuire, RN, BSN, CCTC. “The Impact of Social Media on Living Donation.” Living Donor Conference, May 1, 2019, Wyndham Grand, Clearwater, FL.

local library or transplant hospital.

- Capacity to use social media due to physical limitations such as visual impairments.
- Potential donor age. According to a recent presentation reporting the response at a single transplant center, 64 percent of social media donors were under 40 years old compared to 45 percent of non-social media donors.<sup>17</sup>
- Predominance of platforms that are English-only or are culturally incongruent with selected minorities.<sup>18</sup>
- Educational and socioeconomic differences that influence the ability to tell a compelling story through social media effectively.
- Ability to afford third-party services to manage a social media campaign or to pay to have social media posts “promoted” by the platform.
- Variability in level of social media support transplant hospitals offer to patients.
- Differences by socio-economic status, race, and ethnicity in use of different social media platforms.<sup>19</sup>
- Variability in social media platforms’ algorithms that favor users with a higher number of followers (i.e., “influencers”).

### **Transplant Hospital Administrative Burden**

One of the benefits of patients using social media to find a living donor is the potential to reach a substantial network of people with a keystroke. However, a patient’s social media campaign also has the potential to create strain on transplant hospital resources.

A successful social media campaign has the potential to increase the number of living donor volunteers. This in turn requires a transplant hospital to interact with and educate those who contact the hospital, and to screen and evaluate those who wish to proceed. The rate of conversion from social media-generated interest in donation to donor is uncertain as donor source is not uniformly tracked. The resources required to manage an influx of interested persons can potentially delay the hospital’s ability to identify optimal living donor candidates. Of survey respondents who indicated experiencing challenges related to potential living donors referred by social media, the top three challenge themes were staffing, intake method, and processes or protocols.

Electronic screening tools can facilitate potential living donor screening. These tools are not, however, universally available to users due to cost, lack of internet connectivity, data plans or computers in certain populations and areas of the country. The lack of uniform capacity for transplant hospitals to use these tools to screen potential living donors as efficiently as possible creates disparities across patient populations waiting for transplant.

Of survey respondents who indicated they track potential living donor referral sources, 63 percent reported referrals from social media sites. Of these respondents, 61 percent reported that social media referrals have increased in the past year. About half (51 percent) of survey respondents reported feeling that their transplant hospital is either mostly or very prepared for a sudden influx of potential living donors. The level of perceived preparedness varied geographically. Staffing, intake methods, and

<sup>17</sup> Suzanne McGuire, RN, BSN, CCTC. “The Impact of Social Media on Living Donation.” Living Donor Conference, May 1, 2019, Wyndham Grand, Clearwater, FL.

<sup>18</sup> Carbanaru S, Ortiz A, Ortiz C, Ortiz J, Locke J, Caicedo J. Lack of Linguistically and Culturally Tailored Initiatives in Kidney Transplant Programs in the United States [abstract]. *Am J Transplant*. 2019; 19 (suppl 3). <https://atcmeetingabstracts.com/abstract/lack-of-linguistically-and-culturally-tailored-initiatives-in-kidney-transplant-programs-in-the-united-states/> (accessed December 2, 2019).

<sup>19</sup> “Social Media Use in 2018.” Pew Research Center. <https://www.pewresearch.org/internet/2018/03/01/social-media-use-in-2018/> (accessed December 3, 2019).

established protocols were the most frequently cited drivers of perceived preparedness, with staffing being the primary factor. Those that indicated they have experienced challenges related to the use of social media to find a living donor reported that uneducated or unprepared potential donors and questionable or inappropriate donor and recipient conduct were chief among them. Of transplant hospitals that reported everyday challenges that remain after implementing new practices in response to challenges related to social media, the most frequent were volume of potential living donors, staffing and resources, and donor education, engagement, and accountability.<sup>20</sup>

## Perceptions of Redirected Donation

When a person interested in living donation emerges in response to a patient's social media campaign, some transplant hospitals may assess that person's motivations and commitment to a particular recipient or interest in donating more generally by discussing paired exchanges or interest in non-directed donation. Transplant hospitals may manage potential living donors' expectations by explaining the option of non-directed donation early in the evaluation process. Potential living donors who step forward in response to a social media campaign may opt for non-directed donation. Survey participants were asked if they counsel potential living donors referred by social media who are found to be non-compatible with the intended recipient towards non-directed donation, of which 79 percent indicated that they do. Those that do not counsel patients toward non-directed donation offered the following reasons:

- Lack of experience or not the current practice
- Offer kidney paired donation instead
- Limited resources
- Generally not supportive of the practice<sup>21</sup>

Complexities may arise when a patient's social media campaign generates many potential living donors, such as:

- Should transplant hospitals notify the transplant candidate of every person who responds to a social media campaign, or only those that proceed to evaluation?
- Does the social media campaign owner have a right for exclusive access to volunteers who step forward as a result of the campaign?
- If the patient at the center of the social media campaign is highly sensitized, how many incompatible living donors in kidney paired donation (KPD) are enough and who makes that decision?
- Should a candidate have say in whether and when a transplant hospital presents non-directed donation or kidney paired exchange to donors that the candidate does not know?
- Is it appropriate for a transplant hospital to screen potential donors who step forward in response to a social media campaign for compatibility to other patients (e.g. highly sensitized)?
- If a recipient receives a transplant utilizing one of multiple living donors that they have in KPD and a remaining living donor subsequently chooses to become a non-directed donor, should the initial candidate get "voucher" credit towards a future re-transplant?

## Ethical Challenges for Social Media Living Donor Solicitations

As mentioned above, issues of fairness and equitable access in either using social media or being able to leverage it successfully has continued to be an ethical concern. Variable levels of access to social

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<sup>20</sup> OPTN Descriptive Data Request. "Living Donor Committee Social Media Survey Results." Prepared for Living Donor Committee Meeting, October 4, 2019.

<sup>21</sup> Ibid.

networks might work either for or against certain candidate families when it comes to asking for viable living donor applicants through social media sites.

For example, social media allows users to utilize pictures and videos to generate an intense visual impact on their audience. It also enables individuals interested in directed donation to easily identify patients' attributes, and direct a donation based on what they find most appealing. Thus, social media image sharing and its consequent "beauty pageant" effect, has the potential to unintentionally allow discrimination based on certain characteristics.<sup>22,23</sup>

Not all recipient families are able to financially access social media and internet sites to the same level, thereby generating a sense of "stigma" faced by recipients or families if they are not tech-savvy or do not have social media access. Financial parity within social media usage for generating living donor interest is therefore an ethical concern. Similarly, financial costs of paid donor solicitation websites should be considered separate and distinct from internet access or social media platform access issues. Privacy concerns about jeopardizing living donor identity, such as public expressions of willingness to be evaluated, could be interpreted to mean a willingness to donate, even if the donor proves to be medically or surgically non-eligible for donation. This can effectively create the space for public social media "pressure" for potential living donors to donate against their better judgment, which remains a foreseeable ethical challenge.<sup>24</sup>

## Opportunities

### Opportunity for Increased Patient Communication about the Need for a Living Donor

Studies indicate that the more transplant patients, families, and friends learn about the need for a living donor, the more likely a patient is to find a living donor. In 2018, the Committee reviewed nineteen studies about education programs for patients interested in identifying a living organ donor.<sup>25</sup> The studies were categorized as programs evaluated in randomized controlled trials and programs supported by observational (non-randomized) studies. The studies demonstrated that comprehensive education about living donation and living donor transplantation involves multiple learners - the transplant candidate, potential living donors, and social support networks - and requires communicating complex information about the risks and benefits of donation, transplantation and alternative therapies to these different audiences. Transplant hospitals can help transplant patients learn about living donor transplantation through a variety of formats and modalities, including center-based, home-based and remote technology-based education, outreach to dialysis centers, as well as social media.

Patients, families and friends have long communicated with their own networks about the need for living donors through a variety of means: conversations at work, at church, or on billboards or t-shirts, for example. Social media is an additional indirect communication vehicle to communicate about the need for a living donor quickly, easily and relatively inexpensively with an immediate social network, which can in turn share a patient's content to reach a much broader network. Some patients may be reluctant to initiate discussions with family, friends or others about their disease, their need for a living

<sup>22</sup> "The Organ Beauty Pageant." BBC News. <https://www.bbc.co.uk/programmes/b08nq6fh> (accessed December 3, 2019).

<sup>23</sup> Social Media and Directed Donations, Memo from OPTN Membership and Professional Standards Committee to OPTN OPO Committee. 12 August 2016.

<sup>24</sup> "Living Non-Directed Organ Donation." OPTN. <https://optn.transplant.hrsa.gov/resources/ethics/living-non-directed-organ-donation/> (accessed December 2, 2019).

<sup>25</sup> Hunt HF, Rodrigue JR, Dew MA, Schaffer RL, Henderson ML, Bloom R, Kacani P, Shim P, Bolton L, Sanchez W, Lentine KL. Strategies for Increasing Knowledge, Communication, and Access to Living Donor Transplantation: an Evidence Review to Inform Patient Education. *Curr Transplant Rep.* 2018 Mar;5(1):27-44.

donor and the benefits of living donor transplantation. That reluctance can be eased by the indirect nature of social media platforms that do not require face-to-face interaction. Social media platforms can eliminate awkwardness both for the patient and people who may wish to consider living donation by eliminating any expectation of an immediate response that may be inherent in direct face-to-face interactions.

In the United States, social media is mainstream media. According to the Pew Research Center, 68 percent of adults in the United States used Facebook in 2018.<sup>26</sup> An even greater number indicate that they use any form of social media. One study showed that transplant patients use social media in large numbers, as well. Approximately half of all kidney transplant patients surveyed used social media. About one-third had more than 100 friends in their social media network. Slightly more than half reported that they would be willing to post information about living kidney donation on their social networks and more than a quarter had posted about their health status in the past.<sup>27</sup>

Many adults in the United States carry around “smart phones” or internet-connected devices that enable their regular use of social media. According to the Pew Research Center, the average American household has five internet-connected devices (smartphone, desktop/laptop computer, tablet, streaming media device, etc.).<sup>28</sup> There are, however, significant disparities in access to and use of this technology.<sup>29</sup> That technological gap translates to disparities among patient populations’ ability to use social media to identify a living donor. This presents a pointed challenge to transplant hospitals, as discussed above.

For those who have access to technology and understand how to leverage its benefits, social media platforms offer the potential to democratize access to potential living donors by creating a virtual “town square”. If one has a smartphone or other internet access device and internet data plan, Facebook and other social media platforms are universally available and free to patients, their friends, and family who act as their “champion” to find a living donor.

In recent years, the concept of involving family members and friends to be advocates or “champions” to share a patient’s need for an organ donor with their social network has been advanced, grounded in the premise that removing advocacy from the patient’s duties can mitigate the reluctance to “ask”. One transplant hospital has formally evaluated a “Live Donor Champion” curriculum.<sup>30</sup> The concept has been extended into other programs such as the National Kidney Foundation’s “Big Ask Big Give” workshop and in social media guidelines in the search for a living donor.<sup>31</sup> These efforts resonate with the recommendations of a 2015 American Society of Transplantation consensus conference on best

<sup>26</sup> “Social Media Use in 2018.” *Pew Research Center*. <https://www.pewresearch.org/internet/2018/03/01/social-media-use-in-2018/> (accessed December 3, 2019).

<sup>27</sup> Kazley AS, Hamidi B, Balliet W, Baliga P. Social Media Use Among Living Kidney Donors and Recipients: Survey on Current Practice and Potential. *J Med Internet Res*. 2016 Dec; 18(12): e328. Published online 2016 Dec 20.

<sup>28</sup> “A third of Americans live in a household with three or more smartphones.” *Pew Research Center*. <https://www.pewresearch.org/fact-tank/2017/05/25/a-third-of-americans-live-in-a-household-with-three-or-more-smartphones/> (accessed December 4, 2019).

<sup>29</sup> “Digital divide persists even as lower-income Americans make gains in tech adoption.” *Pew Research Center*. <https://www.pewresearch.org/fact-tank/2019/05/07/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/> (accessed December 4, 2019).

<sup>30</sup> “Live Donor Champion Program.” *Johns Hopkins Medicine*. [https://www.hopkinsmedicine.org/transplant/patient\\_information/live\\_donor\\_program.html](https://www.hopkinsmedicine.org/transplant/patient_information/live_donor_program.html) (accessed December 3, 2019).

<sup>31</sup> “National Kidney Foundation Social Media Guidelines.” *National Kidney Foundation*.

practices in living donation, which emphasized the importance of providing patients and their caregivers with tools and training for identifying and approaching potential living donors.<sup>32,33,34,35</sup>

A prior study evaluated utilization of Facebook pages to help patients find a living kidney donor.<sup>36</sup> Among 91 identified Facebook pages, 31 percent were created by the son or daughter of the potential recipient, and 32 percent by other family members or friends. Of those pages, 32 percent reported living donors being tested on behalf of the patient; there was no significant difference in age of patients who had potential living donors tested and those who did not. Of the 13 Facebook users whose pages reported receipt of a kidney transplant, three received deceased donor transplants, nine received living donor transplants, while one page did not provide enough information to determine the donor type. Reported living donor candidate testing was associated with sharing more potential recipient characteristics, providing more information about transplantation, and higher page traffic.

Some Facebook pages provide templates to patients for creating their own pages directed at finding potential organ donors, though types of services and potential cost vary.<sup>37,38</sup> A Facebook smartphone app developed to enable patients to share their need for a living donor through social media has been formally evaluated.<sup>39</sup> In a pilot study among 54 adult patients without potential living donors at the time of enrollment, the majority of patients using the smartphone app reported it to be “good” to “excellent” with respect to the installation process, readability, simplicity, clarity and content. Compared to matched controls, patients using the app were nearly seven times more likely to have a potential donor come forward on their behalf over ten months after enrollment than patients who did not use the app.

Social media can be a powerful tool for a patient in search of a living donor. Because of the demonstrated increase in use of technology and tools mentioned above, transplant hospitals have the opportunity to offer patients comprehensive education on living donation through a variety of formats to meet different learning needs. Transplant hospitals could include education specific to social media campaigns within their curriculum for patients and their support networks.

## Opportunity to Eliminate Disadvantages

Access to technology (ex. internet connectivity, data plans, and computers) is a prerequisite to using social media to find a living donor. Poor socioeconomic status is a major driver of lower rates of living

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<sup>32</sup> Garonzik-Wang JM, Berger JC, Ros RL, Kucirka LM, Deshpande NA, Boyarsky BJ, Montgomery RA, Hall EC, James NT, Segev DL. Live donor champion: finding live kidney donors by separating the advocate from the patient. *Transplantation*. 2012 Jun 15;93(11):1147-50.

<sup>33</sup> Hunt HF, Rodrigue JR, Dew MA, Schaffer RL, Henderson ML, Bloom R, Kacani P, Shim P, Bolton L, Sanchez W, Lentine KL. Strategies for Increasing Knowledge, Communication, and Access to Living Donor Transplantation: an Evidence Review to Inform Patient Education. *Curr Transplant Rep*. 2018 Mar;5(1):27-44.

<sup>34</sup> “How to find a living donor: Make your transplant happen.” OPTN. [https://optn.transplant.hrsa.gov/media/2458/find-a-living-donor-booklet\\_optn.pdf](https://optn.transplant.hrsa.gov/media/2458/find-a-living-donor-booklet_optn.pdf) (accessed December 3, 2019).

<sup>35</sup> LaPointe Rudow D, Hays R, Baliga P, Cohen DJ, Cooper M, Danovitch GM, Dew MA, Gordon EJ, Mandelbrot DA, McGuire S, Milton J, Moore DR, Morgjevich M, Schold JD, Segev DL, Serur D, Steiner RW, Tan JC, Waterman AD, Zavala EY, Rodrigue JR. Consensus conference on best practices in live kidney donation: recommendations to optimize education, access, and care. *Am J Transplant*. 2015 Apr;15(4):914-22.

<sup>36</sup> Chang A, Anderson EE, Turner HT, Shoham D, Hou SH, Grams M. Identifying potential kidney donors using social networking web sites. *Clinical transplantation*. 2013;27(3):E320-E326.

<sup>37</sup> Find a Kidney Central. In Facebook. <https://www.facebook.com/FindAKidneyCentral> (accessed December 4, 2019).

<sup>38</sup> Kidney Buzz. In Facebook. <https://www.facebook.com/KidneyBuzz-347471888696381/> (accessed December 4, 2019).

<sup>39</sup> Kumar K, King EA, Muzaale AD, Konel JM, Bramstedt KA, Massie AB, Segev DL, Cameron AM. A Smartphone App for Increasing Live Organ Donation. *Am J Transplant*. 2016 Dec;16(12):3548-3553.

donors.<sup>40,41</sup> Such low-resourced areas are predominantly in the Southeast, which also has the lowest living donation rates in the U.S.<sup>42</sup>

An opportunity to mitigate patients' lack of access to technology is for transplant hospitals to make their internet access and computers available to patients to run living donor campaigns. The potential for patients to use transplant hospitals' technology depends on the patients' proximity and transportation. Some parts of the country use telehealth to deliver health care and services to patients in rural areas. Transplant hospitals could consider ways to leverage those resources for transplant patients who need them to conduct a social media living donor campaign. Transplant hospitals could also consider asking local telecommunications providers active in their communities to donate used devices or data plans to transplant patients as they look for a living donor.

### Opportunity for Professionally Vetted Social Media Guidance Documents

Transplant patients are often unsure about how to initiate a social media campaign, from the mechanics of setting up an account to effective information sharing. Transplant hospitals can develop generic social media guidance to help patients use social media to find a living donor in a way that is informed by clinical, ethical and regulatory standards.<sup>43</sup>

Professionally developed guidance for patients can help maximize the value of their time and effort in conducting a social media campaign so that they move beyond the expression of need for an organ without oversharing personal information in a way that presents risk. Such generic guidance can take various forms, for example:

- One transplant hospital developed a Facebook smartphone application to enable patients to share the need for a living donor through social media.<sup>44</sup> In a pilot study, the majority of patients using the smartphone app reported it to be “good” to “excellent” with respect to the installation process, readability, simplicity, clarity, and content.<sup>45</sup>

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<sup>40</sup> Gill J, Dong J, Gill J. Population Income and Longitudinal Trends in Living Kidney Donation in the United States. *JASN* Jan 2015, 26 (1) 201-20. <https://jasn.asnjournals.org/content/26/1/201.full> (accessed December 10, 2019).

<sup>41</sup> Gill J, Dong J, Rose C, Johnston O, Landsberg D, Gill J. The Effect of Race and Income on Living Kidney Donation in the United States. *Journal of the American Society of Nephrology : JASN*. 24. 10.1681/ASN.2013010049. [https://www.researchgate.net/publication/256291388\\_The\\_Effect\\_of\\_Race\\_and\\_Income\\_on\\_Living\\_Kidney\\_Donation\\_in\\_the\\_United\\_States](https://www.researchgate.net/publication/256291388_The_Effect_of_Race_and_Income_on_Living_Kidney_Donation_in_the_United_States) (accessed December 10, 2019).

<sup>42</sup> Shelton BA, Sawinski D, Linas BP, Reese PP, Mustian M, Hungerpiller M, Reed RD, MacLennan PA, Locke JE. Population level outcomes and cost-effectiveness of hepatitis C treatment pre- vs post kidney transplantation. *Am J Transplant*. 2018 Oct;18(10):2483-2495.

<sup>43</sup> Bramstedt KA, Cameron AM. Beyond the Billboard: The Facebook-Based Application, Donor, and Its Guided Approach to Facilitating Living Organ Donation. *Am J Transplant*. 2017 Feb;17(2):336-340.

<sup>44</sup> Kumar K, King EA, Muzaale AD, Konel JM, Bramstedt KA, Massie AB, Segev DL, Cameron AM. A Smartphone App for Increasing Live Organ Donation. *American journal of transplantation: official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2016.

<sup>45</sup> Hunt HF, Rodrigue JR, Dew MA, Schaffer RL, Henderson ML, Bloom R, Kacani P, Shim P, Bolton L, Sanchez W, Lentine KL. Strategies for Increasing Knowledge, Communication, and Access to Living Donor Transplantation: an Evidence Review to Inform Patient Education. *Curr Transplant Rep*. 2018 Mar;5(1):27-44.

- One transplant hospital published a simple step-by-step guide that presented instructions on how to set up a social media campaign, what information to share and not to share, as well as sample social media postings.<sup>46</sup>

## **Opportunity for Continuing Patient Activism, Optimism, and General Social Support**

Finding a living donor rarely happens quickly. Social media platforms are a vehicle through which patients and their support network can sustain activism in looking for a living donor over time and at relatively little or no cost.

Social media is also, at least anecdotally, considered a way to provide important emotional and practical support to patients from social networks, near and far. For example, friends and family of patients looking for a living donor use social media to organize tangible patient support, such as meal delivery or rides, and to generate emotional support by sharing information and encouraging supportive communications.

Finally, some social media platforms such as Facebook provide patients with organized opportunities to share experiences and information with peers through transplant patient networks. A variety of closed network groups exist that are targeted at specific patient populations such as those waiting for a kidney or liver transplant, or those who are post-transplant. These social media-based patient-to-patient communications present similar opportunities and challenges as other peer-to-peer communications: patients often find comfort in talking with peers and so engage freely.

Transplant hospitals could include these examples of potential benefits in addition to potential risks within their patient education on the use of social media to find a living donor.

## **Opportunity for Transplant Hospitals to Educate Potential Donors**

Transplant patients' social media campaigns to find a living donor are an opportunity for transplant hospitals to interact with every person who responds to those campaigns. For example, some transplant hospitals can ensure that everyone who expresses interest in learning more about living donation is informed on how to sign up to be a general organ donor.

Additionally, sometimes a person who is not able to donate to their originally intended recipient expresses a desire to donate to another transplant patient. When this occurs, transplant hospitals may respond by educating anyone interested in living organ donation about other options such as non-directed living donation, initiating a kidney paired donation chain, etc. However, transplant hospitals should avoid actions that could be perceived as coercing or steering a potential living donor to another transplant patient.

Finally, transplant hospitals often use peer-to-peer programs to help educate transplant patients about living organ donation. Multidisciplinary teams that are supported by living donor and patient peers can help ease patients' comfort in talking about living donation. Persons who express interest in living donation, but who do not donate for any number of reasons may be participants in peer-to-peer education.<sup>47</sup>

<sup>46</sup> "Living Donor: A Social Media Toolkit for Champions." University of Pittsburgh Medical Center. [https://www.upmc.com/-/media/upmc/services/transplant/documents/ldlt\\_championtoolkit\\_2018\\_final.pdf?la=en](https://www.upmc.com/-/media/upmc/services/transplant/documents/ldlt_championtoolkit_2018_final.pdf?la=en) (accessed December 3, 2019).

<sup>47</sup> Hunt HF, Rodrigue JR, Dew MA, Schaffer RL, Henderson ML, Bloom R, Kacani P, Shim P, Bolton L, Sanchez W, Lentine KL. Strategies for Increasing Knowledge, Communication, and Access to Living Donor Transplantation: an Evidence Review to Inform Patient Education. *Curr Transplant Rep.* 2018 Mar;5(1):27-44.

Social media campaigns have the potential to generate a large number of potential living donors. If these potential donors are found to be incompatible with the originally intended patient, transplant hospitals can inform the potential donor of other avenues of donation including:

- General organ donor registration
- Non-directed living donation
- Kidney-paired donation (KPD)
- Participation in peer-to-peer education programs

## Patient Guidance: Effective Practices

### Education and Resources

Most survey respondents encounter social media campaigns in some way, with 72 percent of those indicating they provide education to patients wishing to use social media to identify potential living donors.<sup>48</sup> The type, timing, and extent of this education varies substantially. Depending on their transplant hospital practices, transplant patients looking for a living donor may be more or less educated about how to initiate a social media campaign, how to access help from others or have the information they want to share appropriately vetted. The following is a summary of recommendations for best practices to counsel transplant patients on safe and effective utilization of social media to identify potential living donors.<sup>49</sup>

### Timing of Education

While there is some variability in the timing and frequency of transplant hospitals' social media educational offerings, the majority that provide social media education appear to offer it at multiple time points. Of survey respondents who indicated that their hospital offers education on the use of social media, 65 percent indicated they offer education during the initial or intake visit. About a third of the respondents provide additional education during subsequent visits. Of those, 43 percent provide social media education upon patient request and 22 percent do so when patients are actively listed. Some respondents offer regularly scheduled classes, outreach programs, or donor champion programs specific to social media.

To become competent in social media use for living donor campaigning, patients first need to be aware of the potential, receive orientation and guidance, have practice and get subsequent feedback. To that end, transplant hospitals that want to support transplant patients in using social media use to identify potential living donors should remain active in patients' processes over time.

Recommendations:

- Transplant hospitals should offer social media education to patients and their support networks as social media campaigns are often managed by a friend or family member.
- Transplant hospitals should offer this education at multiple points in time throughout the transplant patient's experience, starting with the initial visit.

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<sup>48</sup> OPTN Descriptive Data Request. "Living Donor Committee Social Media Survey Results." Prepared for Living Donor Committee Meeting, October 4, 2019.

<sup>49</sup> Ibid.

## Provider

How a patient receives information depends on who provides the education and when. More than half (58 percent) of survey respondents that educate patients about social media use in living donation provide it through their clinical teams, such as physicians, surgeons, and coordinators. Of these hospitals that provide education, 22 percent rely on an independent living donor advocate (ILDA) or social worker.

Recommendations:

- Transplant hospitals should consider developing a team of “content experts” who together develop a curriculum to provide education to patients and their support networks about the use of social media to identify potential living donors.
- At minimum, transplant hospitals should equip all clinical staff from clinic nurses to physicians who interact with patients to provide basic, consistent guidance on social media use or inform their teams on where to find appropriate resources.
- Transplant hospitals should consider reviewing patients’ social media content prior to the patient posting it in order to ensure the content is appropriate and to minimize misinformation

## Types of Resources

Patients, who in this context are learners, may have different preferences on how to acquire and absorb knowledge (i.e., reading vs audiovisual vs 1:1 counseling). For this reason, transplant hospitals use different types of resources to facilitate patient learning. Of survey respondents whose programs provide social media education, 65 percent provide 1:1 counseling, 42 percent provide brochures specific to their transplant hospital, and 41percent provide group training classes.<sup>50</sup>

Recommendations:

1. Transplant hospitals should develop or acquire educational material that specifically teaches about social medical campaigns to find a living donor. For example, the University of Pittsburgh Schools of the Health Sciences created a social media “toolkit” for living donor champions.<sup>51</sup>
2. Transplant hospitals should offer education in several formats, including, written, audiovisual, and 1:1 counseling in recognition of patients’ diverse learning needs.
3. Transplant hospitals should emphasize to patients that social media campaigns are not right for everyone and not the only means of communication.

## Content

Effective social media campaigns that help patients identify potential living donors rely on invoking empathy, which can lead people to take altruistic actions, such as donating a kidney. Potential living donors are more likely to step forward for an identifiable person rather than a statistic.<sup>52</sup> Thus, social media campaign content is critical. It should communicate the experiences of patients looking for a donor and highlight the need for and benefits of living donation in a way that connects to an individual and inspires empathy.

Transplant patients may have challenges including access to technology, lack of social media proficiency, or unfamiliarity with appropriate content. At the same time, transplant hospitals have continuing

<sup>50</sup> OPTN Descriptive Data Request. “Living Donor Committee Social Media Survey Results.” Prepared for Living Donor Committee Meeting, October 4, 2019.

<sup>51</sup> “Living Donor: A Social Media Toolkit for Champions.” University of Pittsburgh Medical Center. [https://www.upmc.com/./media/upmc/services/transplant/documents/ldlt\\_championtoolkit\\_2018\\_final.pdf?la=en](https://www.upmc.com/./media/upmc/services/transplant/documents/ldlt_championtoolkit_2018_final.pdf?la=en) (accessed December 3, 2019).

<sup>52</sup> Moorlock G, Draper H. Empathy, social media, and directed altruistic living organ donation. *Bioethics*. 2018 Jun;32(5):289-297. DOI: 10.1111/bioe.12438.

concerns about patient privacy, efficacy of social media use, legal and ethical issues, etc. It is therefore imperative for transplant hospitals to provide patients guidance around the use, efficiency, and safety of social media campaigns.

Recommendations:

- Transplant hospitals should develop consensus around what content is appropriate in a social media campaign.
- Transplant hospitals should help transplant patients understand the implications and potential repercussions of sharing private health information in a public forum that displays their personal information permanently.
  - Transplant hospitals should inform patients not to share demographics and other sensitive information such as addresses, social security numbers, and phone numbers on social media but instead through private channels (i.e., personal messaging, emails, etc.).
  - Transplant hospitals should educate patients about the permanent nature of information shared on social media and advise them to consider how current information disclosures could affect them in the future.
- Transplant hospitals should educate patients about rules concerning coercion and pressuring potential living donors.<sup>53</sup>
- Transplant hospitals should make patients aware that after they advertise their need for a living donor on social media, they may likely have no information about potential donors until one donor is approved and that even thereafter, they may never know a donor's identity.
- Transplant hospitals should ensure potential living donors understand patient privacy laws and that communications with transplant hospitals is confidential.

## Administrative Challenges: Effective Practices

### Staffing

A significant consideration to efficiently and effectively evaluating potential living donors is adequate staffing. This is especially crucial if there is a sudden influx of living donor volunteers due to a patient's social media campaign. When survey respondents were asked how prepared they felt their program was to deal with a sudden influx of potential living donors for a single recipient, staffing was the primary concern.<sup>54</sup>

Recommendations:

- Transplant hospitals should provide staff with specialized training to expedite screening of an influx of potential living donors.
- Transplant hospitals should familiarize staff with unique protocols or tools used in the screening of social media living donor candidates.
- Transplant hospitals should evaluate if additional staffing or an adjusted staffing model is possible to respond to social media campaigns.

<sup>53</sup> "Guidance for the Informed Consent of Living Donors." OPTN. <https://optn.transplant.hrsa.gov/resources/guidance/guidance-for-the-informed-consent-of-living-donors/> (accessed December 4, 2019).

<sup>54</sup> OPTN Descriptive Data Request. "Living Donor Committee Social Media Survey Results." Prepared for Living Donor Committee Meeting, October 4, 2019.

## Procedures and Protocols

Another challenge transplant programs face as a result of a social media campaign is determining a potential living donor's motivation or suitability for donation. Also, when there is a sudden influx of volunteers, transplant hospitals can struggle with how to triage those donors effectively. The most common best practice that survey respondents identified was to develop enhanced, custom screening practices for their programs.<sup>55</sup>

Recommendations:

- To reduce the need to correct misinformation, transplant hospitals may choose to work proactively with patients seeking a living donor by providing:
  - Early patient and support network education about risks and benefits to communicate to potential living donors.
  - Sample generic content such as explanations about living donor risks, recovery, and costs, whether through a social media app or otherwise.
- Transplant hospitals should develop a custom protocol specific to efficiently screening and evaluating social media referrals.
- Transplant hospitals should evaluate their resources and determine a manageable limit on number of evaluations done at once.
- Transplant hospitals should determine criteria to prioritize living donor candidates for evaluation.

## Utilization of Tools and Automation of Certain Procedures

More than half (59 percent) of survey respondents indicated their program uses an electronic questionnaire to collect health information for initial screening of living donor volunteers. Of these respondents, the vast majority reported an increase in efficiency with intake of potential living donors.<sup>56</sup>

Recommendations:

- Transplant hospitals should consider utilizing communication tools (ex. voicemail, auto-response, blast email, etc.) to automate and expedite information sharing with a large pool of living donor volunteers.
- Transplant hospitals should consider automating basic screening of potential living donors by using an electronic or online questionnaire.
- Transplant hospitals can use readily accessible online materials, including videos, for orientation and education of potential living donors.

## Conclusion

For a patient with end-stage kidney or liver disease, living donation can expedite their transplant process and offer better outcomes than deceased donor transplantation. As more patients use technology and social media as a tool in their search for a living donor, transplant hospitals should evaluate their patient guidance and administrative practices in order to adapt to the growing trend.

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<sup>55</sup> OPTN Descriptive Data Request. "Living Donor Committee Social Media Survey Results." Prepared for Living Donor Committee Meeting, October 4, 2019.

<sup>56</sup> Ibid.