Asking for Altruistic Organs Using Social media

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The Organ Shortage: Supply and Demand Crisis
Facebook:

- 150 million users in US
- 1 billion worldwide
- “a communication utility”
- “a tool to help you get to know your friends and family better”
The Organ Donor Tool:

- Specify status as organ donor in profile

1) Link to state registry

2) Alert your friends

3) Educational materials
Facebook Donor Tool

- click on “Life Event”

- “declare your status”

- take to DLA’s national website
- tells your friends
The Response:

May 1, 2012: First day:
2,400% nationwide

• First week:
1,000% increase in donor registration

• Totals over 2 weeks: 600%

(Cameron, AJT 2013)
Georgia:

First day: 12,533% (3 → 376)

- First week: 6,022%
- After 2 weeks: 500%
Maryland:

First day: 2,390% nationwide

• First week: 1,225%
• after 2 weeks: 200%
Hawaii:

First day: 800% nationwide

• First week: 417%
• after 2 weeks: baseline
The Facebook Effect

Partnered with Facebook in 2012

Observed 21-fold increase in online organ donor registration

Social media can be used to encourage living donation

Organ Donor...
- Overcame an Illness...
- Quit a Habit...
- New Eating Habits...
- Weight Loss...
- Glasses, Contacts, Other...
- Broken Bone...
- Removed Braces...
- Create Your Own...
Why Living Kidney Donation?

Immediate Impact
Safe surgical procedure
Better outcomes for patients who receive a living donor kidney

Why Not Living Kidney Donation?

LDC Program at JHU

A Smartphone App to Increase Live Organ Donation
DONOR

A web-based application that helps transplant candidates tell their story

WWW.THEDONORAPP.COM
Accessible on Multiple Platforms

LAPTOP. IPHONE. IPAD.

DESKTOP. ANDROID. TABLET
Step 1. Open the Donor App on the Home Screen
Step 2. Start telling your story

Share a little about yourself. What is your name? What are you passionate about? How long have you been diagnosed with kidney failure?

Start typing here...

How does kidney failure affect your life? Are there any activities you miss out on or changes you've had to make? What would a transplant mean to you?

Start typing here...

Let others know that you are looking for a living donor. Encourage friends to share this story and learn how to start a living donor evaluation.

Start typing here...
Step 3. Invite Champions to spread your story

- Champions are close friends or family members willing to help advocate for you and your need for a transplant
- You can invite Champions to tell their own story about your need for a transplant
- This is a good option if you feel hesitant or unsure how to tell your own story
Writer’s block? Click ‘Show Examples’ for sample stories

Find examples here!
Step 4: Add a photo
Step 4: Share your story on social media

Options for sharing

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Barbara needs a kidney transplant. Please click here to see my story and learn how you can help. My kidney dawaaa started with high blood pressure that I did not know that I had. I went to the doctor for a pulled muscle in my back and found out I have high blood pressure and late stage kidney...
Public view of the Donor App post

Viewers can share the story & learn more
Pilot study of the DONOR App

Those who use Facebook are 6.6x more likely to find a donor

Kumar/Cameron AJT 2016
2. Share this story on social media and tag those who might help. 🙌

Dana needs your support. Please share this story for Dana and help find a liver donor who:

- SHARE ON TWITTER
- SHARE ON FACEBOOK MESSENGER
- SHARE ON WHATSAPP
- SHARE VIA EMAIL
- SHARE VIA SMS

425K Retweets
Dissemination of the DONOR App

- 640 patients
- 77 champions
- 331 stories

**Jane's Story Dashboard**

Shared 35 times on 6 channels, resulting in a total of 1667 views.

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**Step 1:** multicenter RCT (R01DK111966)

**Step 2:** 14 active transplant centers, 7 centers in process
Next Steps for the Donor App: Altruistic Donors?

- Curation of Stories
- Promotion of Posts
- Social Media Advertising/Targeting
- Shift posting responsibility away from user
- Behavioral Economics of Altruistic Donation
DONOR

Helping patients find live donors through social media

www.thedonorapp.com

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