

WAITLIST ZERO

Social Media Strategy Memorandum

From: Patrick Andriola, WaitList Zero Social Media Director
To: Coalition to Support Living Kidney Donation
Re: Social Media Strategy
Date: January 1st, 2015

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Introduction

On January 16th, a coalition of organ donation advocates will be meeting with the Health Resources and Services Administration in Washington D.C. to discuss the agency's inaction toward promoting living kidney donation. Leading up to that meeting, we'll be initiating a social media campaign directed at HRSA to demonstrate support for our position. The effort will come from both individual supporters and our coalition of nonprofits. Individual supporters will include friends and family of coalition staff, members of coalition organizations, and people who come across the campaign and want to support our mission. Currently, our coalition of nonprofits includes AAKP, TRIO, Waitlist Zero, and LKDN, though we expect to add other members before the meeting.

This campaign will involve a concerted social media effort that utilizes three main platforms: Facebook, Twitter, and Change.org, each explained in detail below. We will lay the groundwork for this activism over the next two weeks with the intention to publicly launch the campaign on Monday, January 12th, and continue the activity up to and including the Friday meeting (the week will be branded as "Living Donors Week"). This will hopefully build momentum for our cause going into the meeting, and we will plan on additional social media engagement thereafter.

Facebook

Facebook Posts on Member Websites: Our Facebook campaign aims to (1) spread awareness of the issue among our members and their own Facebook

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followers and (2) alert HRSA to support of our policy goals. This will involve separate Facebook posts by coalition members to announce the campaign, kick off Living Donors Week, update members about our progress during that Week, and engage with members who post their own encouragement. During Living Donors Week, each coalition organization will ask its followers to post on their personal Facebook pages, like HRSA's Facebook page, and post a review on HRSA's Facebook page indicating support for our policy.

Timeline: To this end, the week of January 5th, we would like coalition members to make a post to announce their involvement in the campaign. For convenience, WaitList Zero will provide a draft template announcement, which will include instructions to followers about how to post their own content. On Friday, January 16th, each coalition organization will post a brief "teaser" about the upcoming Living Donors Week, and on Monday morning, there will be official kickoff posts followed by daily posts announcing events and progress, such as number of signatures or addition of new coalition members.

HRSA Post Logistics: HRSA has an individual Facebook page found at <https://www.facebook.com/HHS.HRSA>. First, we will ask our members to "Like" the HRSA page (by clicking the "Like" button on the top-right hand side of the screen: a strong uptick in likes will be the first step in grabbing HRSA's attention. Once they have done that, we will ask our members to do two things: (1) review HRSA's page and (2) post on their own Facebook page about the campaign (with an @mention of HRSA to alert HRSA to the post).

HRSA Reviews: On the bottom-left hand side of the HRSA page (which one needs to scroll down or control-f "reviews" to get to) is a section entitled "Reviews." Once you click on that section, you will be taken to HRSA's public Reviews page that allows people to both 1) give HRSA a numerical score on a scale of 1 to 5 stars, and then 2) write a comment regarding their review. We recommend a rating of 3 stars, followed by a comment such as:

"In 2013, twenty thousand more patients with kidney failure joined the waiting list than received a transplant. I truly appreciate HRSA's exemplary work to support deceased donation, but deceased donation alone will never be enough to end this deadly and growing shortage. HRSA needs to join other federal agencies and follow Congress's legal mandate by explicitly supporting policies to increase living kidney donation.

#livingdonorsweek #supportlivingdonors"

After submitting, we suggest your members click on the "Most Recent" tab on the page to see the other campaign comments. By then "liking" those similar comments, we can reach the top of the "Most Helpful" tab, which is driven by how many "likes" comments have.

Individual Facebook Posts: We will also encourage followers to post on their own page with a comment such as:

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“The shortage of kidney transplants claims thousands of lives each year. I support efforts to increase living kidney donation, but @HRSA, the federal agency in charge of organ donation, currently **does not support policies to increase living donation**. That needs to change!

This week, HRSA will meet with patient groups about this life-and-death issue. That’s why I posted this review on HRSA’s website, to show my support for patients with kidney failure:

<text of HRSA review>

Please share this status, like HRSA’s page, and post your own review on their website! Together, we can make a real impact on this life-and-death issue!
#livingdonorsweek #supportlivingdonors”

Twitter

We will continue our activism onto Twitter, where HRSA hosts a page found at <https://twitter.com/HRSAgov>. First, follow them on Twitter if you do not already do so. Then, we want you and your Twitter followers to tweet “at HRSA,” which means including HRSA’s username, @HRSAgov, in the body of your tweets. This notifies HRSA of the post.

The tweet should also include two hashtags: #supportlivingdonors and #livingdonorsweek, placed at the end of the tweet. This publicizes the tweet and allows anyone interested in the issue to read all tweets that contain either phrase.

As an organization, you should be tweeting to encourage your followers to both RT your tweets, as well as inspire them to tweet themselves “at HRSA” and with the hashtags above. The following are examples of tweets we hope to see daily from member organizations during the week of January 12th:

“Please RT to tell @HRSAgov to support policies that increase living donation #supportlivingdonors #livingdonorsweek.”

“Did you know @HRSAgov does not support living donation, despite a Congressional mandate? #supportlivingdonors #livingdonorsweek”

“Please RT if you think @HRSAgov should #supportlivingdonors in order to end our kidney shortage #livingdonorsweek”

“Living donors sacrifice a part of themselves to save a life. Tell @HRSAgov to #supportlivingdonors now! #livingdonorsweek”

You will probably see variations on these from your followers throughout the week, and we encourage you to RT those yourselves. We at Waitlist Zero (our twitter account is @waitlistzero) will also be tweeting nonstop throughout the week, so you can re-tweet us and others that we re-tweet.

Change.org

Change.org is a popular website that allows individuals to sign a petition. By the middle of next week, we will finalize a petition asking that HRSA support living donation, and we will post it at Change.org. Attached as Exhibit A is a current draft of our petition, which will undergo changes before being posted next week. If you have any input, we would love to hear it.

Once the petition is complete and on the Change.org website, there will be a discrete web address for it that we will send out to you. We encourage you not only to sign up for a Change.org account yourselves to sign the petition (you can do this as an individual and as an organization), but also to use your Facebook and Twitter pages (as well as your email lists) to spread the word about the petition to your constituents. For example, a tweet may read:

“We signed the @change petition to demand HRSA #supportlivingdonors. Join us in signing here:”

Although the space after “here” is blank now, once the petition is finalized that is where you can put the web link to the petition. By integrating the change.org petition into our Facebook and Twitter approaches, we’ll have an effective three-pronged social media campaign to demonstrate support to HRSA.

Statement of Responsibilities

We think a coalition works best when expectations and responsibilities are clearly shared and commonly understood. At AAKP’s suggestion we drafted a Statement of Principles explaining what our coalition stood for. Now, we think it may be advisable to develop a Statement of Responsibilities to transparently delineate what each member organization is planning to do for the campaign.

Please see Exhibit B for an initial template of such a Statement. We are eager to hear your feedback about this document and the approach. This is just a template, and the actual Statement will be individualized for each member in the coalition, since capacities and levels of commitment may differ.

Exhibit A

Change.org Petition First Draft

LIVES THAT NEED SAVING

WaitList Zero was founded by two living kidney donors to increase living kidney donation. Co-founder Thomas Kelly's story appeared online in the Washington Post, [here](#).

The organization's other co-founder, Josh Morrison, donated three years ago, to John Mendes, a man he didn't know before giving. Since then, the two have become close friends.

Before receiving a transplant, John was on dialysis for eight hard years. The first time John was dialyzed, the treatment malfunctioned and was so painful he thought he'd rather die than ever go back. Until he received a working kidney, the treatments left him exhausted and barely able to leave the house.

John was young, in good health besides his kidney failure, and a prime candidate for transplantation, but he never asked anyone to donate: he worried that he'd be a burden and that his friends would think transplant surgery was very dangerous (it's not) or would make their lives shorter (it doesn't). His unspoken need for a transplant colored all of his relationships during this difficult period. As he puts it, "It was like a dead body in the room every time one of my friends came over. Both of us knew it was there, but neither of us would talk about it. It was always like: he wasn't offering, and I wasn't asking."

John and kidney failure patients everywhere deserve better. Policies exist that can educate patients and their families about transplantation and to support donors for the financial costs of donation (like their lost wages after surgery) to make it easier for patients to ask for a transplant and easier for donors to give.

Unfortunately, the Health Resources and Services Administration (HRSA), the federal agency responsible for organ donation, **does not support policies to increase living kidney donation** – policies to help patients like John.

HRSA has agreed to meet with a coalition of patient and donor groups to discuss their stance. We need your support to help them rethink their position and make the right decision. **Please sign this petition to ask HRSA to support policies to increase living kidney donation.**

LIVING DONATION IS NECESSARY TO END THE KIDNEY SHORTAGE

Each year, twenty thousand more people go on the transplant waiting list than receive a kidney. That list now numbers more than one hundred thousand, and as many as eighty thousand others need transplants but are never even waitlisted. Yesterday, more than twenty people died because they did not have a transplant. This is an urgent and deadly national tragedy.

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Unfortunately, while efforts to expand deceased donation are valuable, they can never be enough to end the shortage on their own. Fewer than 1% of Americans, about 15-20 thousand each year, die in a way that allows their organs to be transplanted. Of those, about three quarters already donate. Even if every single American gave when eligible, the waitlist would still grow by more than ten thousand each year.

Any policy that condemns thousands to lives without hope of transplant is morally unacceptable. That's why we need to increase living kidney donation. About fifty million Americans are eligible to be living donors, and policies proven to increase living donation exist but have not yet been aggressively pursued by the federal government. Each year, hundreds of millions of dollars are spent procuring deceased donors, but the amount spent to increase living donation is tiny by comparison. **More must be done.**

HRSA AND LIVING DONATION

The Health Resources and Services Administration (HRSA) is the federal agency responsible for organ donation. [One law charges HRSA to make grants "for projects to increase organ donation ... including living donation."](#) Unfortunately, they have still not supported policies that aim to increase living kidney donation. For example, in recent years, HRSA has given out about \$6,000,000 per year under this law, but **they've actually excluded projects to increase living donation from applying for this funding at all!**

HRSA explains the lack of attention towards living donation as due to "the risks associated with any major surgical procedure[.]" Yet this statement ignores the direct benefits to most donors (by saving the life of someone they care about). [Fewer than 5%](#) of donors regret their decision. Meanwhile, other branches of government do support increasing living donation. Medicare pays for thousands of living kidney donor surgeries each year, and the National Institute for Health and the Agency for Healthcare Research and Quality each have funded studies to increase living donation. Congress has approved giving medals to honor all living donors and passed a law that explicitly "recognizes the generous contribution made by each living [donor]." Nevertheless, HRSA's crucial position in the organ donation field means that other federal support is not enough.

HRSA deserves tremendous credit for bringing the deceased donor system to maturity through its contract with the United Network for Organ Sharing (which administers the waitlist). No such system exists for living donation, but that's what we need, a systematic approach that provides: universal payment for donor lost wages; universal transplant education for the public, patients, and their families; universal access to paired kidney donation for those with incompatible donors. We need HRSA's help to make these dreams a reality.

PETITION

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We call on HRSA to:

1. Publicly support the goal of increasing living kidney donation;
2. Allow grant funding, including that pursuant to 42 U.S. Code §274f-1(b), to go to projects intended to increase living kidney donation;
3. Allocate such funds in rough parity between living and deceased donation projects; and
4. Include metrics and goals related to the increase of living donation on their FY 2016 Annual Performance Report and future Annual Performance Reports.

Exhibit B

Sample Statement of Responsibilities

_____ (Coalition Member) is proud to support efforts to increase living kidney donation and intends to play a critical role in the campaign to persuade HRSA to change its living donation policies. To assist with planning and implementing the campaign, _____ (Coalition Member) commits to:

Public Affiliation

- 1) Being listed as a Coalition Member on the WaitList Zero website and in other communications material.
- 2) Publicly referencing its membership in the Coalition on [its website], Twitter, and Facebook.

Solicitation of Member Support for the Campaign

- 1) During the week of January 12-16th, posting on its Twitter and Facebook feed at least once a day about the campaign and publicizing member engagement with Living Donors Week through liking Facebook content and retweeting supportive messages.
- 2) Making best efforts to recruit ## letters of support to HRSA, ## comments on HRSA's Facebook page, and ## Change.org petition signatures.
- 3) Inclusion of campaign description in at least one membership newsletter or other email to organization members.
- 4) Being a strong social media partner as the campaign strategy evolves after the January 16th meeting.

Organizational Involvement

- 1) Designating one staff member as point person responsible for the campaign, including solicitation of member support.
- 2) Participating in a monthly meeting to discuss campaign strategy.