

WAITLIST ZERO

Hi I'm Josh Morrison. I'm a kidney donor, am Secretary of the Coalition to Promote Living Kidney Donation and am Executive Director of WaitList Zero, which represents the interests of living kidney donors. On behalf of the Coalition and the four other stakeholders here today, I'd like to thank everyone at HRSA for having this meeting and for the absolutely critical, life-saving work you do to ensure and expand equitable access to organ donation. We truly appreciate all your work.

We're all here today because there is a kidney transplant shortage crisis in this country.

Scale

- Each year, twenty thousand more patients go on the waiting list than receive a transplant. That's about 2/3 the number of auto accident deaths or gun fatalities in the United States, but as we all know, our field receives far less attention.
- That might actually understate the true need. According to research of AST Board Member Jesse Schold, as many as 80,000 patients may be medically eligible for a transplant but never even make it to the list.

Disparate Impact

Now we all know a core part of HRSA's mission is to promote health equity and access. So I know that the disparate impact of kidney disease on people of color is as painful to HRSA as it is to myself, and the rest of the attendees. At every stage, kidney disease has a disproportionately harmful impact on people of color, especially those of African descent.

People of African descent develop chronic kidney disease at a higher rate than Caucasians.

- Their CKD is more likely to result in end-stage renal disease.
- They're less likely to receive a preemptive transplant.
- They're less likely to be waitlisted for transplant.
- They wait longer to receive a transplant once they're on the waiting list.
- And they are less likely to find a living donor.

Problem Is Getting Worse

- Unfortunately, the problem is getting worse rather than better. Total transplant rates have been flat since 2006.
- 2014 was the worst year for living donation in 14 years. In that time the American population has increased by 40 million people and the waiting list

has doubled to more than 100,000 patients. This means that despite kidney paired donation, payment of travel costs through NLDAC, and wider adoption of laparoscopic nephrectomy, access to living donation has declined dramatically in this century.

So clearly, we are facing a crisis.

Now we around this table all know this, and we all appreciate the importance of taking action to solve this crisis, which is what brings us here today. As the stakeholders to the living donation field, it is we who are responsible for ending this crisis and it is we who must take ownership of it.

So with that introduction I want to now lay out an overview for the meeting.

- First thing to say is that each stakeholder group speaks for itself, so we shouldn't attribute statements from any one group to the attendees as a whole. With the exception of a couple areas of agreed-upon consensus items, which I'll identify shortly, everyone's views are their own.
- Second is that I know the Coalition naming can be a bit confusing, since it can imply that all the stakeholders here are part of the same Coalition. That's not the case. There are five different stakeholders. The Coalition to Promote Living Kidney Donation is one. The other four are the American Society of Transplantation, the American Society of Transplant Surgeons, Donate Life America, and the National Kidney Foundation.

Our five stakeholders have formed a consensus on two points:

- First, that HRSA ought to allow for grants to support educating the public, patients, and their families about living donor transplantation. We all agree that living donor transplant education is important and needs to be prioritized at the federal level.
- Second, that this collaboration between our stakeholder groups and HRSA on living donation issues should be ongoing and should not end with this meeting.

So now that that's out of the way, beyond that everyone's views are their own. I should also mention that Thomas will be writing up minutes and we'll distribute them after this meeting.

I want to talk about the Coalition as one of the stakeholders and say a bit about us and our goals.

The Coalition was founded at the beginning of the year and over the past eight months has grown to fifteen members including the American Association of Kidney Patients, the Alliance for Paired Donation, Transplant Recipients International Organization, and my own group WaitList Zero.

Our goals are in our Statement of Principles, which you'll find in the printouts Thomas handed out.

Our main goal, as our name implies, is to promote and to increase living kidney donation. Now I know that that goal is one that is shared by Donate Life America and the National Kidney Foundation, and I hope we'll hear more about AST and ASTS's views at today's meeting. But I also know that that's a goal that HRSA has been uncomfortable with in the past, so in my remaining time, I want to lay out our logic on this very important point.

As I understand it, the concern is that HRSA feels that living donation is a personal choice and that since it does not confer a direct medical benefit on the donor, the government needs to take a stance of neutrality towards it.

Now, while I respect that the sentiment behind this stance is genuine and heartfelt, it is one I disagree with. And I want give four reasons for that:

1. It's inconsistent with government practice;
2. It ignores the tangible benefits of donation to donors;
3. It ignores that kidney donors are well-informed and satisfied with their choice; and
4. To increase donation is merely to bring it back to a previous high-water mark which was considered completely unproblematic at the time.

First, a discomfort with promoting living kidney donation is inconsistent with government practice.

Now of course, other agencies within HHS like AHRQ and NIH do provide grants for the purpose of increasing living kidney donation.

But even more conceptually, the government encourages better individual health choices all the time. For example, the government encourages: healthier diet, exercise, annual checkups, mammograms, and compliance with drug treatment.

But even if we only confine ourselves to choices that confer benefits on others rather than on oneself, the government also encourages vaccination, blood donation, deceased organ donation, prenatal health and breastfeeding, and, I think most analogously, military service.

I simply cannot see the logic by which the federal government encourages service in the armed forces but fails to encourage living kidney donation.

Second, kidney donation has tangible benefits for the donor.

Most donors give to people they care deeply about. The donors lives are often better, often in material ways, when their spouse or child is alive and not on dialysis. It is simply incorrect to think this decision represents some sort of pure sacrifice.

Third, there is literally no evidence that kidney donation is anything but a well-reasoned and well-informed decision for donors.

Numerous studies have repeatedly found that over 95% of donors are satisfied with their decision; something that I think can be said for few other medical procedures.

Those in our society with most access to medical care and expertise richest people donate the most.

According to research of AST Board Member John Gill, a white donor from a zip code within the top income quintile is three times as likely to donate a kidney as someone of African descent located in the bottom income quintile. Given that African Americans are overrepresented on the waiting list by three times, that shows how widely access to living kidney donation varies by socioeconomic status, and that people who are the best-informed donate at dramatically higher rates.

Fourth, as I mentioned before, access to living donor transplant by patients on the waiting list has been cut in half since 2000. There was no evidence at that point that donors were being coerced or making a poor decision. Simply bringing current donation rates back to where they were in 2000 would double living donation, and unless there was a problem then, I don't see why there'd be a problem now.

Now that all said, I recognize that part of the discomfort with encouraging living donation is the concern that more can be done to better establish its health consequences. That's something we will talk about today, but it's something that affects me personally so I want to take a moment to speak about it now.

When I donated, in 2011, no studies had compared living donors to matched controls. It had not yet been found that living donation increases the risk of lifetime ESRD by about one percentage point. And even now, of the nine studies comparing donors to healthy matched controls, only two have median follow-ups greater than 9 years, neither of which took place in the U.S. Clearly, part of living donor transplant policy needs to be an increased focus on understanding donor risk, increasing follow-up study and care, and rationalizing and making transparent transplant center criteria for donation.

But that said, what I can also say on behalf of the donors represented by WaitList Zero is that no one, and I mean no one takes the decision to donate a kidney, to remove an organ through surgery lightly. Everyone knows there are risks and uncertainties. Donors do it anyway to save a life. The government should honor that choice and treat it as one worth encouraging.

Now obviously I find these points persuasive, but I don't pretend that I will have convinced everyone of our Coalition's case. So let me take a step back as I wrap up to state a goal I think we can all get behind.

Whether or not we think the government should encourage kidney donors to donate, clearly, we should encourage patients to seek living donation, and I think we can all behind policies of transplant support, to make it easy to ask for a donation and easy to give. To support the decision to donate and make it as costless and well-informed as possible.

That means educating the public; that means educating patients and their families, helping patients learn how to ask, and supporting the donor by removing disincentives, by offsetting risk, by honoring their decision, disseminating best practices in the field, and ensuring long-term care and study. There is a great deal of work to do to achieve these goals, but I am confident we can all agree that these goals are worth pursuing.

Thank you.