

COMMUNITY



ADVOCACY



EDUCATION



# NATIONAL KIDNEY DONATION ORGANIZATION

We are devoted to helping end  
the kidney crisis in this country.

OCTOBER  
2021

NK  
DO



# IN THIS ISSUE

|   |           |
|---|-----------|
| <b>Mission Statement.....</b>   | <b>3</b>  |
| <b>NKDO Expands Donor Connect to Transplant Centers.....</b>            | <b>4</b>  |
| <b>NKDO to Increase Living Donor Campaigns for Kidney Patients.....</b> | <b>5</b>  |
| <b>NKDO Team Gathers on Martha’s Vineyard.....</b>                      | <b>6</b>  |
| <b>NKDO In The News.....</b>  | <b>7</b>  |
| <b>NKDO Within the Hispanic/Latino Community.....</b>                   | <b>8</b>  |
| <b>Update From the Organ Trail 2.0.....</b>                             | <b>9</b>  |
| <b>Gallery.....</b>   | <b>11</b> |
| <b>Thank You To Our Sponsors.....</b>                                   | <b>12</b> |



## NKDO MISSION STATEMENT

---

The mission of the National Kidney Donation Organization is to save lives by making living kidney donation more accessible through education and awareness, and to remove obstacles to such donation. NKDO also works with kidney patients to assist in navigating the route to kidney transplantation.

## BECOME A MEMBER OF NKDO!

National Kidney Donation Organization is the largest living donor advocacy organization in the country. We need your help to increase our ability to effect changes which benefit donors and recipients alike. All donors have the right to be properly informed so that they can donate effectively and with the most protections available. You can help by becoming a member of NKDO. There is no cost associated with becoming a member. You will be enrolled in our new Facebook members' group, and you may opt-in to be notified of developments in transplant that may impact you. You will receive the NKDO Newsletter and you will be invited to participate in periodic Zoom meetings with industry experts. Please sign up at <https://www.nkdo.org/nkdo-membership>.

# NKDO EXPANDS DONOR CONNECT TO TRANSPLANT CENTERS

---

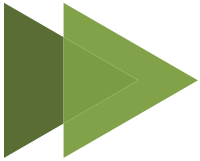
Since March of 2021, an NKDO team has been mentoring donor candidates who apply through the National Kidney Registry. The goal of the Donor Connect program is to increase the number of living donors. These mentors explain the testing, donation, and recovery process and share the protections available based on the donor's transplant center. The mentors maintain contact with the candidates throughout the evaluation process and are available to answer non-medical questions.

The success of Donor Connect has come to the attention of some key transplant centers, and this month the program was implemented at Georgetown Transplant Center and Hackensack Meridian Transplant Center. Once the NKDO mentors review the experience with the donor candidates, those individuals are better prepared to connect with their center's Living Donor Coordinator. This results in a more efficient use of time by the LDCs and a higher conversion rate

of candidates into living donors. NKDO is discussing the Donor Connect program with several other transplant centers and we'll share updates in the January newsletter.

If you are a living donor and you would like to be considered for an NKDO donor mentor position, please contact [i.lemmott@nkdo.org](mailto:i.lemmott@nkdo.org). She will explain the training program and the other requirements to be an NKDO mentor. If you are an LDC or another transplant center professional and would like to learn more about Donor Connect, please contact [nedbrooks@nkdo.org](mailto:nedbrooks@nkdo.org)





## NKDO TO INCREASE LIVING DONOR CAMPAIGNS FOR KIDNEY PATIENTS

In earlier newsletters we discussed the campaign to find a kidney donor for Marc Weiner, and the success of this effort. To understand the impact these campaigns can have, it is important to understand how to successfully manage these initiatives. When a kidney patient launches a campaign to find a donor on social media, they usually ask interested parties to contact their transplant center. This often overwhelms the transplant center and they simply cannot handle those numbers in a timely or efficient fashion. Additionally, many of the potential donors may be geographically distant from the patient's center, and they may not be aware of remote donation via a voucher donation options.



Campaign for  
Marc Weiner, NY



Kyle Willis

By organizing a donor campaign like Marc Weiner's ([kidney4marc.org](http://kidney4marc.org)), all candidates register with NKDO on behalf of the patient. The NKDO mentor speaks with the candidate and explains the donation process, the standard voucher program versus direct donation, remote donation, and the ability for a number of candidates to be evaluated simultaneously at different centers. The candidate is also asked if they are willing to consider proceeding as a non-directed donor (NDD) or family voucher donor if the original intended recipient receives a kidney or voucher through another donor. In Marc Weiner's campaign, he received a voucher from a donor at NYPH Weill Cornell while another candidate was still being tested. That candidate still proceeded as an NDD at Barnabas Hospital. But the campaign

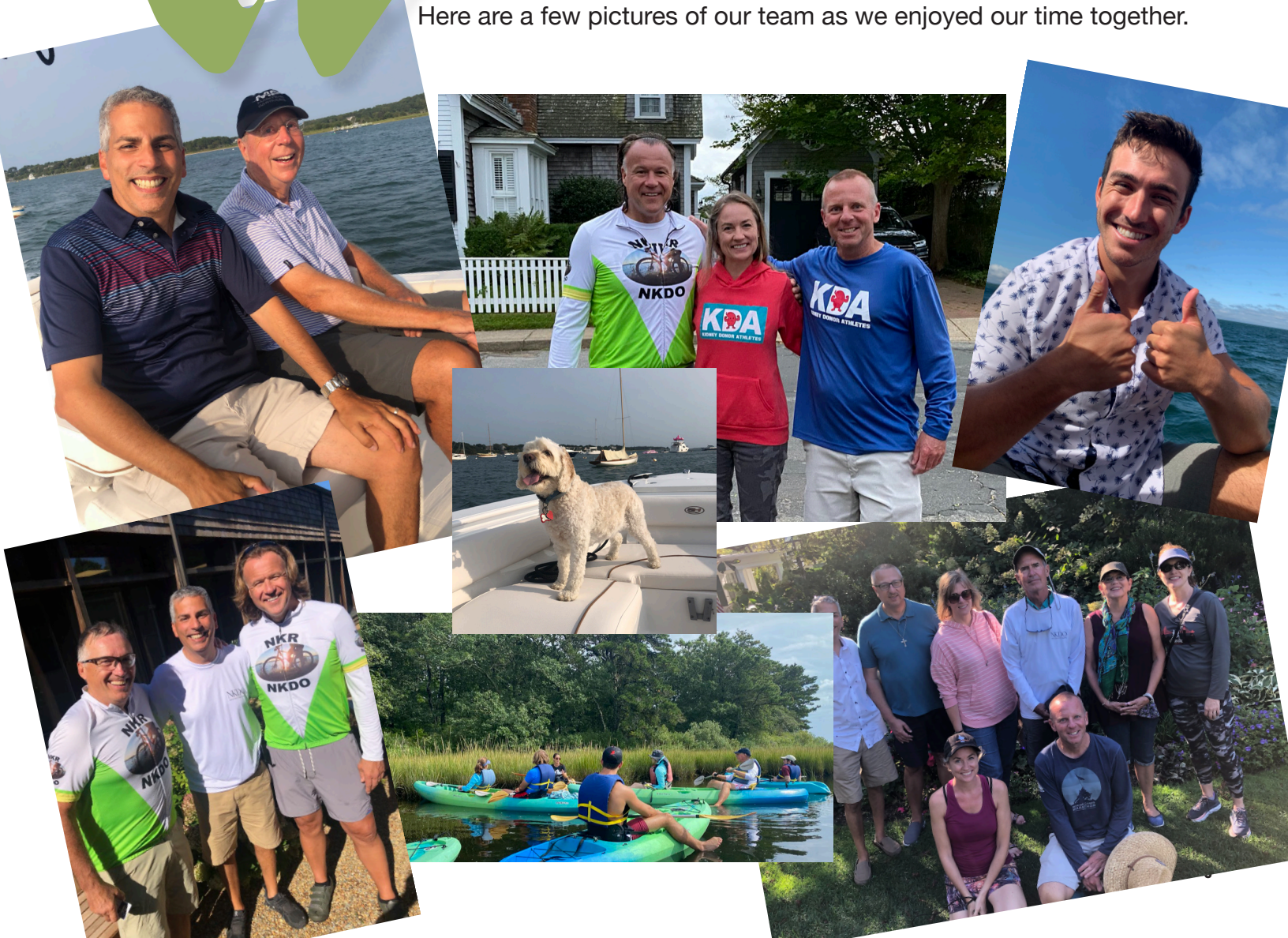
continues as two more candidates are completing the evaluation process as NDDs! This successful campaign for Marc Weiner gave him a voucher, took nine additional patients off the wait list because of the additional donors, and no one center was overwhelmed with candidates because of the involvement of the NKDO mentor team.

A new campaign is now under way - [Kidney4Kyle.org](http://Kidney4Kyle.org). We believe this campaign will help all parties involved and take multiple patients off the wait list by converting some of the candidates into NDDs or family voucher donors. If you have interest in learning more about how to work with NKDO to initiate a campaign for a patient awaiting a transplant, please contact [info@nkdo.org](mailto:info@nkdo.org).

## NKDO TEAM GATHERS ON MARTHA'S VINEYARD

The NKDO team is serious about our mission, but all work and no play makes Jack a dull boy. So last month we traveled from across the country to gather in Edgartown, on the island of Martha's Vineyard, for a combination of continuing education, team building and just plain fun. We were fortunate to have two veteran Living Donor Coordinators, Marian Charlton of Hackensack Meridian and Ellen Simpson, recently retired from Cleveland Clinic in Weston, FL, attend to give updates on life in transplant as viewed by an LDC. Joe Sinacore brought us up to speed on new programs at the National Kidney Registry.

The event also served as the starting point for The Organ Trail 2.0, which kicked off from the Martha's Vineyard Hospital on September 19. Here are a few pictures of our team as we enjoyed our time together.





# NKDO IN THE NEWS

## PODCASTS:

Several recent podcasts feature NKDO folk. Laurie Lee's podcast "Donor Diaries" interviews Ned Brooks about the voucher donation programs. This link includes the subsequent podcast from the Vineyard at our conference <https://open.spotify.com/show/32GX7VsT9PB58lgAIGKq0K>.



LAURIE LEE



NED BROOKS



MIKE LOLLO

DR. GARY SHERMAN

The Heart Guy interviews Mike Lollo here: <https://www.buzzsprout.com/1736386/9242574?fbclid=IwAR1nxosJlj3uDANZmTURkJYjobK-PreHw1xONTZ23NM3rxuemO5HeUkrBHas>.



Why Donate Our Kidney to a Stranger?

85 views • Oct 5, 2021

LIKE DISLIKE SHARE SAVE ...

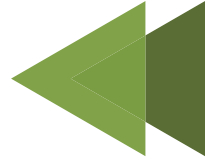
NKDO team member Elaine Perlman asked NKDO team members why they donated their kidney to a stranger; it's a casual and spontaneous discussion which may be viewed on the YouTube NKDO channel here [https://www.youtube.com/watch?v=p9m-m\\_YjMh8&t=7s](https://www.youtube.com/watch?v=p9m-m_YjMh8&t=7s).

In other developments, NKDO President Michael Lollo has been selected to be on the AST Transplant Community Advisory Council. Congratulations, Mike!



MIKE LOLLO

## NKDO WITHIN THE HISPANIC/LATINO COMMUNITIES



Our team is working hard at highlighting kidney donation awareness within our Hispanic/ Latino communities. There are various current initiatives in development that will provide support to non-English speaking (Hispanic/ Latino) potential donors and recipients. The need is clear due to the fact that Hispanics or Latinos are 1.3 times as likely as non-Hispanic/ Latinos to develop kidney failure (source: NKF September 15, 2021).

NKDO's goal is to add and train culturally attuned Spanish-speaking mentors/ coaches to support our donor and patient programs, that will target to enhance our presence within limited English-speaking Hispanic/ Latino communities.



## UPDATE FROM THE ORGAN TRAIL 2.0 - MARK SCOTCH, OCTOBER 12, 2021

Note: Mark Scotch donated his kidney on behalf of a man he met in a bar through the NKR voucher program. After his donation, he rode his bike in early 2021 on the original Organ Trail to Louisiana to reconnect with this man. On his ride, he created awareness about kidney disease and the need for living kidney donors. The Organ Trail 2.0 started on September 19 in Martha's Vineyard and will end at Mark's home in Plover, WI.



While I write this, I'm in a Muskegon, MI hotel, the day before

we ferry across to Milwaukee, WI. The trip has been a whirlwind that began Sunday, Sept. 19, in Martha's Vineyard, MA. But Lynn and I only have 5 days to go before we are home in Plover, WI.

The Organ Trail involves so many moving parts. In addition to riding the bike, there were media stops, connecting with hosts, sharing the story of those in need of a kidney, visits to dialysis programs, meeting transplant medical staff, and staying current on Facebook. Lynn's support role in our van has been a major factor in our success. She has picked me up on deserted roads to get me to a media appointment, brought me a sandwich with a side of encouragement, kept our lodging schedule straight, and kept us both in clean laundry! Lynn also spent time listening to people's stories and offering encouragement as kidney patients search and wait for a kidney.

To date, I've kept 61 media events while on the Trail – this includes TV, newspaper, podcasts, radio, Facebook, and Twitter. Compared to the first Organ Trail ride earlier this year, podcasts and radio interviews have been more frequent.

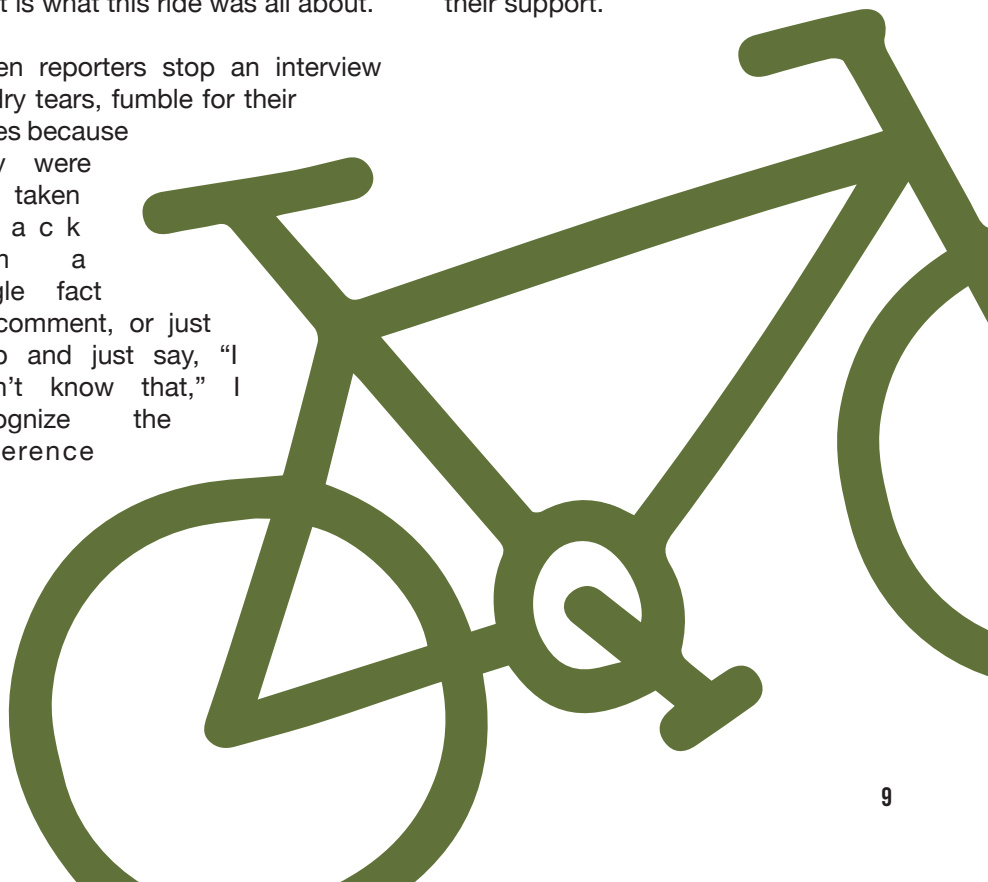
Lynn and I are grateful that several lodging hosts were the result of contacts made through Kidney Donor Athletes. Even though we had never met our hosts before, it was like we were getting together with life-long friends.

Especially gratifying for me was being able to meet people waiting for a kidney who were willing and able to meet me along the trail. I will continue to work to get their story out after the ride is over. Of particular interest to me is learning, while on the Organ Trail, that a family friend needs a kidney. Our sons attended school together 25 years ago. I will do what I can to share his story. That is what this ride was all about.

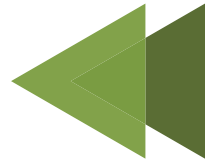
When reporters stop an interview to dry tears, fumble for their notes because they were so taken a b a c k from a single fact or comment, or just stop and just say, "I didn't know that," I recognize the difference

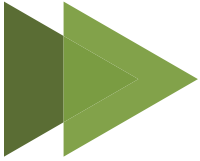
we're making. This happened during my first Organ Trail ride from my home to Louisiana to meet my voucher recipient, and it also occurred frequently during this ride.

All stops are special, but one of our final events will be at our grandson's junior high school the day before we arrive home. And while this will be an easy stop to engage in, traveling by bicycle builds in the dimension of not moving too fast, of paying attention to those we encounter, and to make certain no one is passed by. There is time for everyone and everything. Without NKR.org and NKDO.org there wouldn't be The Organ Trail, so we thank them for their support.



## PICTURES FROM THE ORGAN TRAIL





## OCTOBER GALLERY: OUR MERRY BAND OF KIDNEY DONORS





## SPONSORS

---

We want to thank our charitable donors and our corporate sponsors in 2021, [Transplant Genomics, Inc \(TGI\)](#) and [NxStage](#). TGI is sponsoring the NKDO YouTube channel and we will continue to build this library of expert interviews as a resource for both donors and transplant recipients.

Thank you,  
Ned Brooks, CEO  
[nedbrooks@nkdo.org](mailto:nedbrooks@nkdo.org)

**SUPPORT OUR MISSION**