



NATIONAL KIDNEY
DONATION ORGANIZATION



FALL NEWSLETTER

OCTOBER 2022 | [NKDO.ORG](https://nkdo.org)

 COMMUNITY  ADVOCACY  EDUCATION



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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!

- No cost associated with becoming a member.
- You will be enrolled in our new Facebook members group
- You may opt-in to be notified of developments in transplant that may impact you.
- You will receive the NKDO Newsletter
- You will be invited to participate in periodic Zoom meetings with industry experts.

<https://www.nkdo.org/nkdo-membership>

THE DONOR NETWORK NEWSLETTER

We take this opportunity to welcome the team who produced the Donor Network newsletter since 2018. They are living donors who support and report on the activities of the National Kidney Registry, and their insights now have a home as part of this newsletter, see their section below.

ATC CONFERENCE

This past June, NKDO CEO Ned Brooks and NKR Chief Operating Officer (COO) Michael Lollo were invited to present at the American Transplant Congress (ATC) conference about the living donor experience. The ATC event is the premier annual conference in transplant, and Michael and Ned's participation was the first ever by non-medical professionals. Attendance at the session was standing room only and the message was clear – the living donor experience has an important place in the evolving discussion about transplant. NKDO's role as the largest advocacy group for living donation and a voice for better protections for living donors continues to grow.



NKDO YOUTUBE CHANNEL



EXPERT INTERVIEWS

We continue to grow our library of expert interviews on our YouTube channel https://www.youtube.com/c/NKDO_Channel. Our recent interviews include Dr. Suzanne Ildstad, Chief Scientific Officer at Talaris Therapeutics. Talaris is engaged in Phase 3 and Phase 2 trials for a therapy that has the potential to eliminate the need for immunosuppressive drugs for recipients of organ transplants, which would be a watershed development in transplant.

We interviewed Dr. Jon Friedman, the Chief Medical Officer for Transplant Genomics Inc (TGI). TGI focuses on diagnostic solutions to identify signals of graft transplant rejection at a very early stage so that corrective measures may be taken to prevent loss of the transplanted organ.

These interviews focus on different areas of transplant which serve to inform the lay viewer of important developments in transplant.

DONOR CONNECT

Our team of over 45 living donors serve as mentors for donor candidates at the transplant centers affiliated with the National Kidney Registry. NKDO partners closely with 27 centers to help donor candidates to better understand the donation experience by speaking with someone who has donated and can provide first-hand experience of the process. This program supports NKDO's belief that no one can talk to a potential donor with more authority than someone who has donated. We have reached out to over 14,000 donor candidates to date, and that number continues to grow, as shown in this chart:



The goal of the program is to increase the percentage of donor candidates who continue through the process to become donors. The path to becoming a kidney donor can be challenging, and many opportunities exist for the process to end before the candidate can donate. Our mentors helped guide 34 candidates to donation in the month of September. These numbers have been increasing steadily, and we are excited by the impact our team is having on the numbers of living donors in this country.

RISC

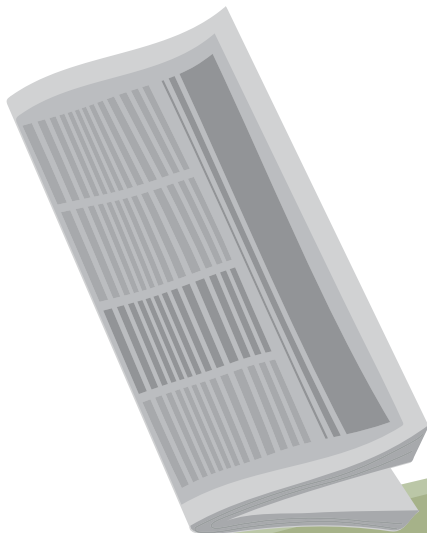
RADICAL INNOVATION FOR SOCIAL CHANGE

The Center for RISC is the brainchild of Steven Levitt, professor of economics at the University of Chicago and co-author of *Freakonomics*. A team at RISC created Project Donor to work with potential living kidney donors who have been screened out of the donation process due to high BMI or the need to stop smoking. Project Donor fully funds weight loss and coaching programs for these individuals to help them achieve a BMI and non-smoking status that makes them eligible for donation testing. In addition to partnering with specific centers for academic study of these candidates, the Project Donor team reached out to NKDO because of our access to living donor candidates. NKDO mentors can now refer candidates directly to the Project Donor team. This partnership has been well-received by both transplant centers and potential donors.



THE DONOR NETWORK NEWSLETTER

This donor network began the summer of 2018 with a Donor Open House, hosted by the National Kidney Registry (NKR). This newsletter, while supportive of the NKR, is independent of the NKR, and the views expressed are those of the authors. In the spirit of collaboration, we seek to engage NKR donors in continued fellowship as we share goals and hopes for a more compassionate society. We give generously of ourselves and inspire others to do the same.



We have enjoyed sharing all the news and NKR updates with you every month since 2018 and have benefited greatly from our work to build community and inspiration among our readers. We hope you have too. Please continue to send in your good news kidney stories to rachelou@hotmail.com so they can be circulated more broadly.

Please see the
October newsletter here:

<https://docs.google.com/document/d/1F5OiuE1CstukQsiR6qrEz4GZrCbUZJgyVsgC69YDcshU/edit>

KIDNEY DONOR ATHLETES IN THE NEWS

INCOMING NKDO PRESIDENT MATTHEW CAVANAUGH



Matthew Cavanaugh begins his role this fall as the incoming president of NKDO, following Michael Lollo's move from NKDO to become the COO of National Kidney Registry. Matthew just completed Race 3 of the Racing the Planet – 4 Desert Ultramarathon Series. This third leg took place in the Atacama Desert in Chile, the highest desert in the world at +16,000 feet elevation. For many of us, breathing at that altitude is a challenge. Now imagine running 250 kilometers over 6 days, carrying all your gear on your back. As he did in the Race 1 through the desert of Namibia and Race 2 in the desert in the Republic of Georgia earlier this year, Matt finished in a solid third place. He has six weeks to prepare for the fourth race in Antarctica.

Why is Matthew, who donated his kidney as a non-directed donor to start a chain of eight transplants in 2021, doing this extraordinary feat of endurance? "About seventy percent of Americans believe that living kidney donation results in some form of permanent physical impairment for the donor," he says. He adds, "Nothing

could be further from the truth – and we want to break that myth by showing how kidney donors can do not just ordinary activities, but we can and do participate in some of the most demanding physical activities humans can devise."

You can read Matthew's blog on all the stages of the races here:

<https://www.kidneyregistry.org/for-donors/kidney-donation-blog/1k4d/>



KIDNEY DONOR ATHLETES IN THE NEWS

HILARY BAUDE

Sometimes competitive athletes become kidney donors, and sometimes kidney donors go on to compete in remarkable feats of physical achievement. NKDO's Hilary Baude is a combination of both. Hilary is an elementary school teacher by profession, and also runs marathons. Hilary donated to a stranger to give a kidney voucher to Marc Weiner, a New York City resident.

Hilary leaving the hospital to return home the day after her donation



Hilary found inspiration to up her game by getting to know fellow donors who are remarkable athletes, particularly NKDO's Steve Wilson. She recently gave herself a remarkable challenge by entering and completing her first Ironman competition. Not only did she complete the 140.6 miles of swimming, cycling, and running, but she placed near the top for her age group. We applaud Hilary and we suspect that will not be the last time she does something extraordinary.

Hilary running the marathon portion of the Ironman competition

NKR DONOR GAMES

As part of ongoing efforts to correct public misperception about the effect of kidney donation on a donor's health going forward, the National Kidney Registry sponsors a periodic competition of donor athletes and showcases that kidney donation does not impair a donor from engaging in all manner of physical activity. The recent competition in Connecticut was won by NKDO team member and living donor, Cody Maynard. Cody describes the event:

The 2022 Donor Games championship hosted by the National Kidney Registry took place September 17, in Stamford, CT. Kidney donor athletes, transplant recipients, and advocates from across the country gathered to compete, raise awareness for living kidney donation, and demonstrate that living kidney donors can live active, healthy lives post donation. Approximately 20 people participated in the championship games. The championship is by invitation only and is held annually, with other opportunities to participate virtually throughout the year.

There were three different elements of the competition; one of them is the Murph workout which is performed in the following sequence and timed for rank: one-mile run on the open road, 100 pull-ups, 200 push-ups, 300 air squats, another one-mile run. There is a time limit of 1 hour and 15 minutes for the full workout.

Cody sums up the gift of living kidney donation in the following way. "If someone is drowning in the water beside you, would you throw them an extra life jacket to save them? How about your kidney?"

Cody Maynard and Mimi Mahon (pictured right) are both living kidney donors, and they are the winners in the men's and women's categories, respectively:

Visit <https://www.livingdonorgames.org> to learn more.





SPONSORS

We want to thank our charitable donors and our corporate sponsors, [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
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