



The MTN Minute

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A Message from the Editor



Summertime is in full swing, which means it is time for another edition of the MTN Minute to keep you informed of Midwest Transplant Network's (MTN's) legislative activities and provide you a summary of the spring legislative session. Although in-person legislative visits and events were suspended for most of spring session, MTN remained active in speaking with legislators at the state and federal level to discuss proposed organ procurement organization (OPO) performance metrics, lobby lawmakers for changes that would safeguard transplant activity during the pandemic, and advocate for legislative changes that would promote the use and efficacy of OPO-managed organ recovery centers (ORCs) and/or donor care units (DCUs). Additionally, MTN's President/Chief Executive Officer, Jan Finn, RN, MSN, has accepted an appointment to serve as the Association of Organ Procurement Organizations' (AOPO's) President for the 2021-2022 term. This will allow Finn to be at the center of legislative and policy discussions that will impact not only MTN, but also the entire OPO community and transplant centers nationwide. Finn's appointment as President-Elect of AOPO coincided with the publication of a peer-reviewed article stating that MTN ranked first in the nation based on its organ donation rates in 2017, 2018 and 2019. [1]



As you can see, there is much to be excited about at MTN; however, MTN, like all OPOs nationwide, experienced a substantial reduction in transplants at the beginning of the year. Despite the surging coronavirus pandemic, employees continue to fulfill MTN's mission each day. This volume is especially dedicated to the MTN heroes who have been working tirelessly throughout the pandemic to ensure the continuation of transplant activity in western Missouri and Kansas. MTN's clinical staff members have remained flexible over the past six months while working in local hospitals, adapting to new protocols, and remaining resilient and innovative in the face of new challenges to organ donation and transplantation. Due in large part to the hard work of these MTN employees, MTN carried out the wishes of 153 donors between January and June, which is a decrease of only one donor compared to the same time period in 2019 (154 donors). MTN also had a record-breaking June, recovering organs from 30 donors — the most donors ever recovered by MTN staff members in the month of June, and MTN is anticipating that July will also be a record-breaking month! We are grateful to MTN's clinical staff in addition to MTN employees who work in Donation Services, Family Services and Hospital Services for their tireless work and hope you will keep their contributions in mind as you enjoy this volume of the MTN Minute.

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[1] Niroomand, Elaheh & Mantero, Alejandro & Narasimman, Manasa & Delgado, Cindy & Goldberg, David. (2020). Rapid Improvement in OPO Performance: Potential for Change and Impact of New Leadership. *American Journal of Transplantation*, 11-12. 10.1111/ajt.16085



Kidney Advocacy Day at the Capitol

National Kidney Foundation (NKF) representatives joined MTN staff members Nichole Asquith, Elizabeth Gonzales and Salama Gallimore in visiting the Kansas State Capitol on

March 10, 2020, to educate lawmakers about the prevalence of kidney disease in the United States. Volunteers and employees representing MTN and NKF informed legislators that 33% of adults in the U.S. are currently at risk for kidney disease, and 39,000 individuals were added to the kidney waitlist in 2019, because the need for healthy kidneys far surpasses the current supply. During a legislative breakfast near the Capitol rotunda, NKF staffers and volunteers informed Senators and Representatives that the optimal treatment for most patients with kidney failure is transplantation; moreover, studies show that the best-functioning, longest-lasting type of transplant comes from a living donor.^[2]

Following the breakfast, MTN staff members set up booths and engaged in casual discussions with legislators about the need to pass legislation to prohibit discrimination in life, disability or long-term care insurance against living donors. Additionally, MTN staffers informed lawmakers about the need to support legislation that would extend Medicare coverage for immunosuppressive medications needed by transplant recipients to maintain their kidney and lower the risk of rejection. MTN employees also informed legislators and the general public about the benefits of organ donation and dispelled commonly held misconceptions regard organ donation and transplantation. MTN and NKF representatives had a meet and greet with Governor Laura Kelly, pictured below.

[2] National Kidney Foundation (NKF). Kidney Transplant. *Kidney.org*. Retrieved July 14, 2020, from <https://www.kidney.org/atoz/content/kidney-transplant>

Bill Tracker for Spring Session 2020

- **MTN supported SB 551** which prohibited discrimination in insurance against any person based solely on the person's status as an organ donor in Missouri. This bill was **signed into law by Governor Mike Parson on July 14, 2020.**
- **MTN supported HB 1709**, which added protections relating to insurance for living organ donors in Missouri, so insurers are prohibited from considering an individual's status as a living donor in the offering, issuance, cancellation, price or conditions of an insurance policy. **Relevant HB 1709 language was included in SB 551 and passed into law.**
- **MTN supported SCR 33**, which designated August as Minority Organ Donor Awareness Month in Missouri. **This bill progressed through committee in both houses but was not adopted.**
- **MTN supported SB 712**, which modified provisions relating to anatomical

gifts to individuals with disabilities to ensure those individuals received equal access to donated organs in Missouri. **Relevant SB 712 language was included in SB 551 and passed into law.**

- **MTN opposed HB 2228**, which required lethal injections to be administered in a manner that allowed consenting inmates to donate organs. MTN opposed due to logistical and ethical considerations that make condemned inmate donation highly impractical, if not impossible. **This bill died in committee.**



CEO Jan Finn Tapped by AOPO to Serve as President-Elect

On June 22, 2020, AOPO named Finn its President-Elect. Finn has previously served in leadership roles within the North American Transplant Coordinators Organization (NATCO), the United Network for Organ Sharing (UNOS) and within AOPO, serving on the organization's Executive Committee, advancing lobbying efforts through her work on the Legislative and Regulatory Affairs Committee and effecting change on various other AOPO councils and committees. When Finn begins her term as AOPO President in 2021, she will serve as a leader of the 58 federally designated OPOs in the nation. Finn will be charged with leading the strategic planning process, collaborating with AOPO councils, and advocating nationally to advance and improve the efficacy of organ donation and

transplantation.

“I am honored to represent MTN, those in our service area and the entire OPO community,” Finn said. “AOPO is actively involved in advocacy for all donor families and recipients in ensuring each OPO strives for excellence in donation practice to ensure desperately needed organs for transplantation, and I am happy to lend my voice to such meaningful work.”

Please join MTN in congratulating Finn for being honored with this important responsibility that is representative of her 30-year commitment to this lifesaving work and thanking her for her untiring dedication to improving the OPO community.

Public Comment Follow Up: New Guidelines Aim to Reduce Risk and Increase Organ Acceptance

The previous volume of the MTN Minute included a summary of a public comment drafted by Dr. Taba Kheradmand, Finn and Gallimore in response to proposed revisions to the 2013 U.S. Public Health Services (PHS) Guideline for Reducing Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV), and Hepatitis C Virus (HCV) through Organ Transplantation. In its public comment, MTN supported efforts to reduce the risk of disease transmission while saving lives through organ donation and transplantation. However, MTN advocated to eliminate the “increased risk” designation for organs because of the chilling effect on organ acceptance, perceptions that the risk is higher than the true risk for disease transmission, and lack of association between “increased risk” designation criteria and significant risk of HIV, HBV and HCV infection/transmission. Additionally, MTN cautioned against the proposal that PHS require additional sample collection 24 hours prior to organ recovery, because this would create logistical hurdles for OPOs and increase the time and cost of transplants without providing meaningful information.

On June 26, 2020, PHS published new guidelines designed to encourage the safe transplantation of organs, particularly where donors may have been at risk for HIV, HBV or HCV. Advances in testing for these infections have made results highly accurate, and accordingly, have drastically reduced the risk of transmission during transplant. PHS’ recommendations for solid organ procurement and transplant practices directed OPOs to discontinue labeling HIV, HBV or HCV at-risk donors at “increased risk” to avoid unnecessarily deterring organ acceptance and increasing the time to transplant. Additionally, transplant centers are directed to inform patients that the risk for undetected transmission of HIV, HBV, and HCV is low and explain the effective treatments for these infections.

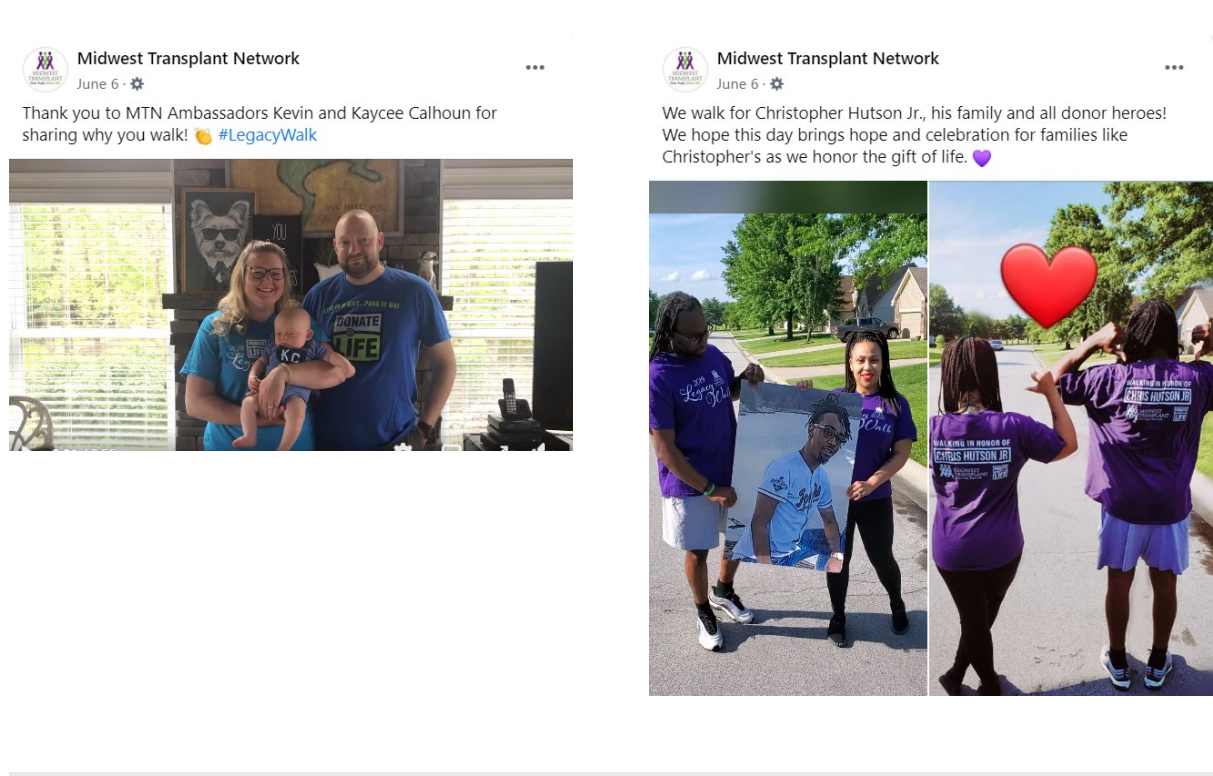
Under the new guidelines, transplant centers are also required to advise potential recipients that accept an organ from a donor with increased risk factors may increase their chances of survival. Unfortunately, PHS opted to require OPOs and living donor recovery centers to collect donor blood specimens within 24 hours before organ procurement, which MTN anticipates will create operational and logistical complications for OPOs related to obtaining qualified samples, because these samples may be scarce or nonexistent and increase the cost of transplants, which will ultimately be passed onto the recipients awaiting lifesaving transplants and their families. Despite PHS’ decisions regarding 24-hour testing, MTN remains hopeful that PHS’ revisions related to organs with an augmented chance of transmitting HIV, HBV and HCV will encourage an upsurge in organ acceptance and a reduction in transplantation risk.



Reimagining the Legacy Walk in a Virtual World

On June 6, 2020, MTN held its fourth annual Donate Life Legacy Walk to honor and remember donor heroes and transplant recipients. The walk, which was originally scheduled as an in-person celebration, was reimagined as a virtual celebration. The all-day virtual event was an extreme success, thanks to the efforts of MTN’s Community Education (CE) team. Please enjoy a sample of the posts shared by virtual walkers on MTN’s social media page. MTN reached over 15,000 people via Facebook and almost 1,000 people via Instagram during the virtual walk and recognized select participants with spirit awards, including Best Video, Best Sign and Most Spirited. MTN’s CE team is motivated to outdo themselves and are already contemplating even more exciting

surprises for next year’s Legacy Walk on **June 5, 2021!**



Upcoming Projects and Initiatives

- **Together, We Save Lives** – Donate Life America has previously celebrated Donate Life ECHO in July, and the Association for Multicultural Affairs in Transplantation has celebrated National Minority Donor Awareness Week at the beginning of August. The organizations combined these two initiatives to bring awareness to the multicultural need of organ, eye and tissue donation. They now have dedicated the entire month of August to these efforts.

MTN’s campaign — launching this August — will be focused around the theme “Together, we save more lives.” Follow Midwest Transplant Network on social media to see the great information and stories that will be shared throughout the month.

- **Legislative Activities Webpage** – MTN will launch a fully redesigned website later this year, and the new site will include a newly created Legislative Activities page! In anticipation of this new space for legislative information and insights into MTN’s advocacy, please submit any requests for information and/or content to sgallimore@mwn.org.



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