

# U.S. Organ Donation System Future: Successful Fusion of Diversity, Equity, and Inclusion Mandatory

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## INTRODUCTION

The purpose of this paper is, very simply, to increase organ donation and thus save more lives by advancing racial equity and support for underserved communities in the nation's organ donation system. Lack of equity has plagued our transplantation ecosystem as well as the overall healthcare system in this nation. As noted in Executive Order (EO) 13985, *"equal opportunity is the bedrock of American democracy, and our diversity is one of our country's greatest strengths. Entrenched disparities in our laws and public policies, and in our public and private institutions, have often denied that equal opportunity to individuals and communities. Our country faces converging economic, health, and climate crises that have exposed and exacerbated inequities, while a historic movement for justice has highlighted the unbearable human costs of systemic racism. Our Nation deserves an ambitious whole-of-government equity agenda that matches the scale of the opportunities and challenges that we face."*

Organ donation and transplantation illustrate these challenges perhaps more than any other healthcare endeavor due to the interconnectedness of the 'giving' and 'receiving' participants in the donation and transplantation process. This giving and receiving dynamic, along with the concomitant potential, perceived and real pitfalls of systemic racism, the lack of diversity, equity and inclusion throughout various organizations and healthcare in general and the transplant ecosystem, deserve our special attention and system-reform action. This is a bipartisan issue; organ donation saves lives across the nation.

Current data indicates that following the introduction of CMS' OPO performance metrics, organ donation increased. We know that further increases in donation are possible by increasing donation rates across all race/ethnicities, and likely the largest gains in organ donation will be achieved by work done within our communities of color as well as our own organizations (OPOs and hospitals).to increase donation rates. . For industries to drive mission and individual organizational success, the future is unequivocal: full integration of diversity, equity, and inclusion (DEI) must be a cornerstone of the foundation of our ecosystem. As an organizational imperative, DEI is not a fad; it's here to stay. Focusing on DEI is not only the right and socially responsible thing for an organization to do, but also what is best for the success of our nation's donation and transplantation ecosystem in saving lives.

Organizations, in this case OPOs, must change to effectively serve their community, by becoming part of the same rich tapestry that is the community. Our challenge is to create systems for

generations to come. Sustained effort in the DEI sphere has positive bottom-line benefits – and in the donation and transplantation industry, our bottom line is ‘more lives saved.’

There are plenty of reasons to address racial disparities in an initiative-taking, in-action way. Firstly, it is the right thing to do to be in touch with our character as an equal opportunity nation. But as importantly in the field of organ donation, addressing this issue forthrightly is a strong component for the remedy to our donation and transplantation system we are seeking to achieve – that of increasing organ donation. In other words, DEI is good for organizational success; our success being measured in lives saved.

Advancing racial equity and support for underserved communities in our nation’s donation system will require direct and therefore actionable goals. It has long been both an observation and an excuse that minorities do not donate. That is not true. We made the following recommendations in recent public comments, 2020-2022 and list them below again in service of advocating for a call to action on these concrete and potentially tipping-point recommendations.

**RECOMMENDATIONS:**

**By purpose, practice and regulation, Centers for Medicare and Medicaid Services (CMS) promulgate regulations that:**

1. Define proportionate requirements for racial and ethnic composition of OPO staff, including leadership staff, clinical staff, donor family service staff and overall staff composition (all of organization).
2. Define proportionate requirements for racial and ethnic composition of the OPO governing board.
3. CMS share Donation Rate by Ethnicity, by OPO, in its CMS’ public report.
4. Establish OPO benchmarking of potential minority donor (non-white) donation rates as well as volumetric rankings with the same denominator methodology as used in the CMS OPO performance determinations.
5. Define expectations for donation rates of potential minority donors (non-white).

## **NARRATIVE**

### **COMMUNITIES OF COLOR AND THE CMS FINAL RULE**

We believe that seeds of change were sown in the Final Rule to improve donation rates amongst minorities. Over time, through nuanced and representational involvement, we believe the rule will help reduce disparities across a broad spectrum of donation and transplantation care.

Minorities donate. In some parts of the country, minorities donate at the same rate as do Non-Hispanic Whites. Thus, equal donation rate can be achieved when the DSA functions as a true community. New census population projections confirm the importance of racial minorities as the primary demographic engine of the nation's future growth, countering an aging, slow-growing and soon to be declining white population. It is projected that the nation will become "minority white" in 2045. During that year, whites will comprise 49.7 percent of the population in contrast to 24.6 percent for Hispanics, 13.1 percent for blacks, 7.9 percent for Asians, and 3.8 percent for multiracial populations. The shift is the result of two trends. First, between 2018 and 2060, gains will continue in the combined racial minority populations, growing by 74 percent. Second, during this time frame, the aging white population will see a modest immediate gain through 2024, and then experience a long-term decline through 2060, a consequence of more deaths than births.

We believe that OPO performance measured in terms of increasing the number of donors and organs transplanted is possible with an intentional and actionable focus on diversity, equity, and inclusion (DEI) throughout OPO organizational staff, operational policies, and board governance. To achieve the gains needed to significantly increase the number of organs recovered and transplanted, to reduce deaths on the waitlist, we will have to do a better job with such inclusive actions to increase minority authorization rates. With cultural humility, our organizations will be better able to focus on and understand the diversity and needs of our community. When our organizations demonstrate cultural humility and competence, we can tap into non-traditional ways of getting our communities to start the conversation in order that they will be informed, ready and willing to donate when presented with that situation. That they may know someone in their community who has received a transplant, or works in transplantation or donation, obviously demonstrates to them that this is their community's lived experience as well. They can trust and believe that they are a fully valued and equal part of the donation and transplantation ecosystem.

During the public comment process, CMS rejected the concept of racial/ethnic risk adjustment before its issuance of the Final Rule. Adjusting donation rates by race/ethnicity across OPOs does not cause organizations to find ways to reach and effectively collaborate with communities of color and would codify the current situation of a lack of accountability by OPOs for performance, which has created a public health crisis in availability of transplantable organs, especially for minority patients. Proposals to "risk adjust" by, for example, gender, race, and socioeconomic status as determined by the patient's zip code, provides no incentives for OPOs to 'meet families where they are' and develop communication competencies for culturally diverse individuals.

Acknowledging demographic reality without codifying racial/ethnic donation rate adjustments that obscure our motivation to change to effectively live and work within our respective communities is counterproductive. The new rule will help reinforce the actions of OPOs to change our organizations and thus our donation system to reflect their communities we serve. To be successful, and to the extent they have not yet done so, OPOs will build the type of organization

that can obtain more lifesaving donated organs, changing the face of the organization to reflect the same rich tapestry that is the community. Accountability for OPO performance very directly leads to more lives saved through increased organ donation. As earlier stated, donation rates across all race/ethnicities can be increased, however critical improvement is immediately needed in our communities of color. Viewing, representing, engaging and calling-upon racial/ethnic minorities, while not 'risk adjusting' them into invisibility and thus irrelevance, will grow the deep roots needed to create the substantive changes our organizations and institutions must make to eliminate systemic racism and the organ shortage.

OPO staff who are successful in obtaining donor authorization must be able to (1) relate well to families and hospital staff, (2) spend significant blocks of time with families without interruption, (3) explain brain death in terms the family can understand; and in summary and overarchingly, connect with the family, fully exploring opinions and/or objections to donation. That this might be easier to accomplish, during the time-compacted donation scenario, when the family and requestor share visual, experiential, and expressive traits seems intuitively apparent, and was thus included in the final change package produced by the Organ Donation Breakthrough Collaborative (ODBC). While obtaining authorization is about more than who we put in front of the family to make the request, there can be no question that nonverbal connections are made between people based on a myriad of factors, including an individual's collective life experience and other factors that predispose a family to be open to a connection at a stressful time. OPOs should keep this in mind as they build the type of organization that can obtain more lifesaving donated organs. *Communities are. Organizations are.* They should reflect their mutual environment in at least their most vital component, *their people.*

Our comments and recommendations focus on OPO staff and governance reflect community diversity in a visual, proportional way. It seems apparent that without regulation, a lack of DEI will continue to remain a 'topic' given lip service but little action and thus not become our new reality, our new norm in the future. Seriously and objectively addressing this issue **means** equal representation in the structures of power and decision-making. The topic of diversity amongst OPOs has been discussed for decades yet little has changed. Statements such as "Diversity is important, but..." and "Not a culture fit" (similarity bias), reveal the reluctance to change leadership and operations that could cause temporal disruption to the status quo therefore often resulting in organizations that are largely white, particularly at the leadership and executive leadership level. Hiring bias is real. Change is hard. In our industry's case, however, such change will offer benefits and most of all, save more lives. It is an added benefit that a positive by-product of such change will be the creation of resilient, healthy, and results-focused ecosystem workplaces.

In EO 13985, all governmental agencies were clearly directed that the agencies "*pursue a comprehensive approach to advancing equity for all, including people of color and others who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality...* and acknowledged that *...affirmatively advancing equity, civil rights, racial justice, and equal opportunity is the responsibility*" of those agencies." We believe that as federally certified and regulated organizations, OPOs share these same equity and justice ideals. Certainly, our donation and transplantation ecosystem is built on public trust, dependent on the public at large, and thus we should read ourselves into these executive orders addressing issues of health equity.

Our donation and transplantation ecosystem's results will not be achieved through vague and 'future-visioned' pronouncements, as is generally the current state of affairs in DEI matters. *"Advancing equity requires a systematic approach to embedding fairness in decision making processes"* in our organizations to *"recognize and work to redress inequities in their policies and programs that serve as barriers to equal opportunity."* There is no question that this is our ecosystem's work. We ask the public, regardless of race or ethnicity, to register as donors, we approach families during tumultuous times, to donate organs upon their death. That domain must be, and must be seen as, an open, transparent and an equal opportunity endeavor. When we achieve that open, transparent, and equitable environment, we will see that change reflected in our results and ability to serve our communities.

By advancing equity across our OPOs and the entire transplant ecosystem, *"we can create opportunities for the improvement of communities that have been historically underserved, which benefits everyone. The Federal Government's goal in advancing equity is to provide everyone with the opportunity to reach their full potential."* OPOs, transplant centers and other ecosystem stakeholders must assess whether, and to what extent, *"its programs and policies perpetuate Ensuring* that people of color are embedded throughout our organizations and decision-making-structures should be a foundational requirement. We can start with who we are and who we serve.

OPOs will benefit from critically examining their formal and informal leadership as well as governing structures to ensure that the organization reflects its community. Agency or accrediting body reviews of OPO staff racial/ethnic composition are non-existent, or if they do exist, are outdated and even if examined, are likely perused for the superficial overall numbers of minority staff. There is no provision in CMS regulations, thus none in the CMS Interpretive Guidelines, for a provision defining proportionate representation of people of color (POC) within the organizations, various departments, the leadership team, or the governing board and how that compares to the various communities served by the organization. At this point, regulations are needed to require such organizational restructuring.

Any community service organization with substantive minority/ethnic populations benefits from visually, experientially, and expressively reflecting their community. It is a given that organizations provide diversity training, however, the question at this point in the evolution of our organ donation system and specifically of organ procurement organizations (OPOs) deserves to be asked: can such training, excellent as it is, take the place of an organization truly reflecting its community in the manner just described? While perhaps the answer to this as well as other such questions is not fully known, likely most of us could say that when we see a successful donation milieu/environment/team, *we know it*. This leads us to the 'time is now' discussion.

## **RECOMMENDATIONS – THE TIME IS NOW**

The dramatic and sustained gains in organ donation needed across the country will not be achieved without the full participation of minority communities in the donation process. Achieving and holding those gains will require systemic change in the donation and transplantation organizations that serve the nation. Minorities often doubt the justice and the equity of our country's healthcare

institutions. Put simply, wrongs must be acknowledged and corrected to advance equity and access and reduce systemic racism in the donation and transplantation ecosystem.

We urge CMS to maximize incentives to build diversity into the donation and transplantation ecosystem. The beneficiaries of CMS' work include all potential donors, donors, donor families and the patients awaiting transplantation. To examine racial equity in the donation system, very direct and actionable regulations that engender trust in the system should be considered with the goal of moving towards equity in access to transplantation and for the opportunity for all people of color to say "yes" to donation.

No other agency has been as influential as CMS on OPO and hospital donation processes during the history of donation and OPOs. The regulations promulgated by CMS over the years have fundamentally changed and strengthened hospital/OPO practices and requirements that have led to significant increases in organ and tissue donation. Those of us in the field for a significant amount of time remember when OPOs had little weight behind their requests for meaningful changes in hospital-OPO interactions related to referral, donor management and hospital cooperation. CMS changed that. We are now at the point, and have been for some time, in which CMS' rule making can result in its next significant life-saving accomplishment by refocusing the nation on increasing the absolute number of organs donated and therefore the number of patients transplanted. This cannot be done without greatly increasing focus on communities of color and their participation in the donation process. Such focus cannot put the burden on those communities. We have all heard 'minorities don't donate,' however as mentioned earlier, this declaration is not useful; our mindset needs to be turned towards starting our work at home by reflecting our communities. These recommendations are in no way the universe of what will be needed to fully achieve our aims, but we believe them to be the bedrock and measurable beginning of our industry's efforts to increase donation amongst all communities served.



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# REFLECTING OUR COMMUNITY: *Communities of Color and their OPO*

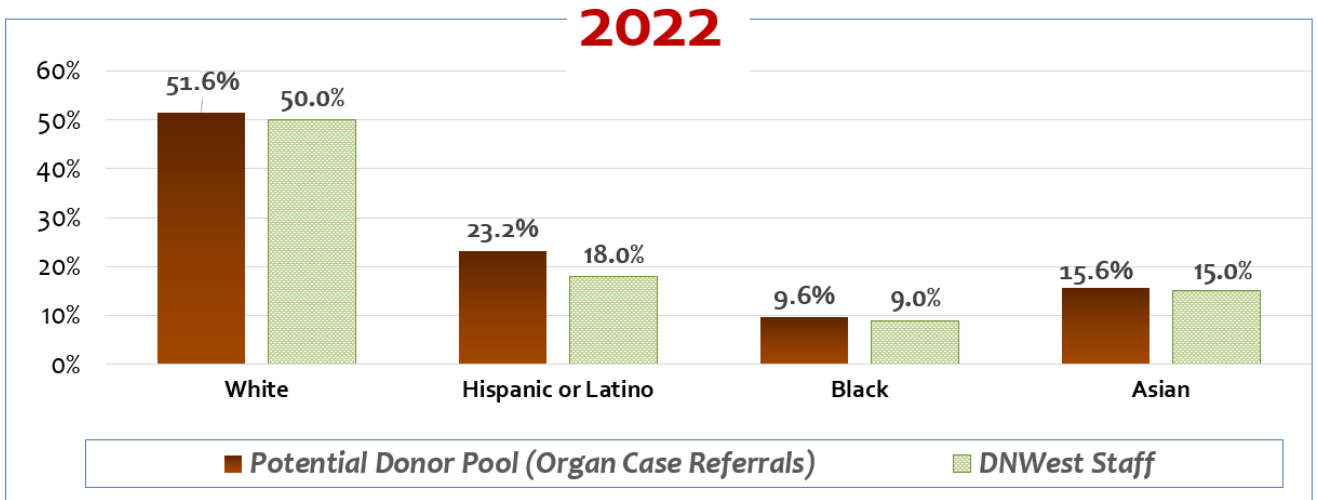
## OPO CASE STUDY: Donor Network West

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Solutions

# REFLECTING OUR COMMUNITY

## DNWest Staff Race/Ethnicity compared to Potential Donor Pool (Potential Donors & Families we serve)

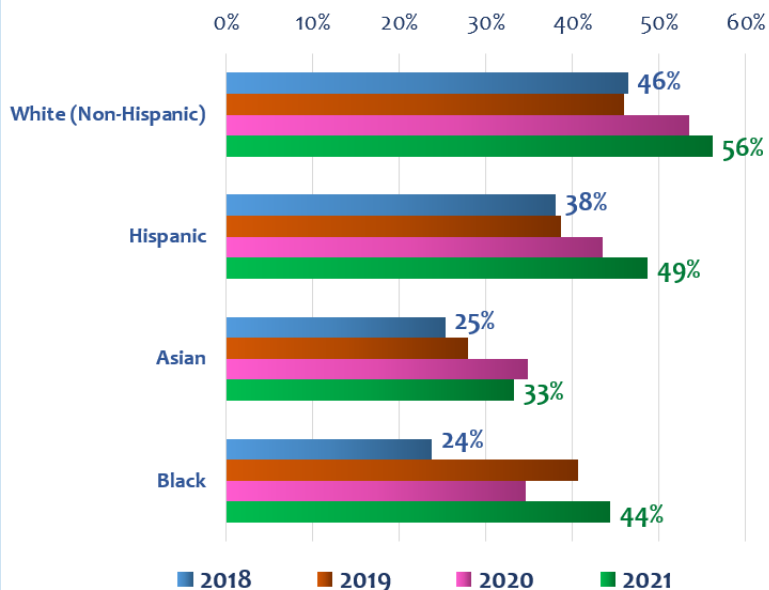


Race/Ethnicity of potential donors and Race/Ethnicity of Donor Network West Race/Ethnicity. Source for Potential Donor Pool and for DNWest Staff Race/Ethnicity: DNWest

DONOR NETWORK WEST

# FOCUS ON SERVING COMMUNITIES OF COLOR

## Donor Network West Authorization Rates by Race/Ethnicity



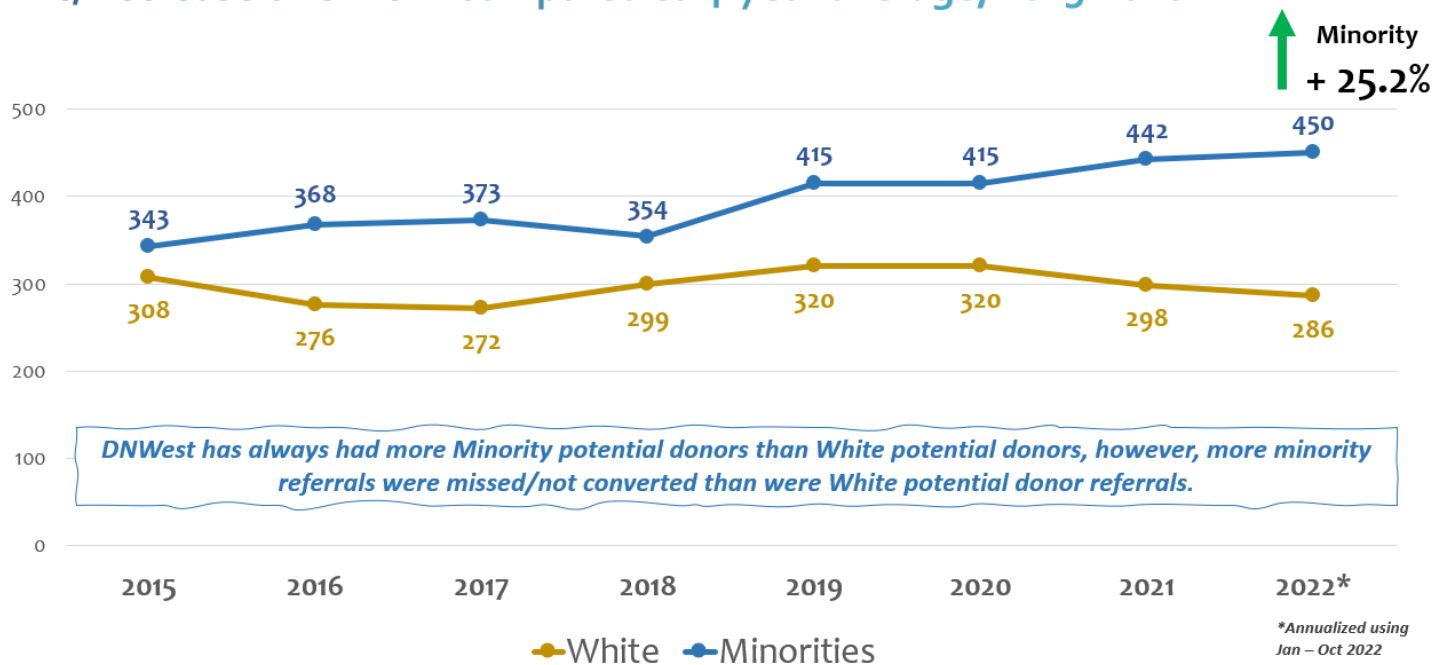
### Global Authorization Rate by Race/Ethnicity (non FPA), 2018 to 2021

- 22% increase, White (Non-Hispanic)
- 29% increase, Hispanic
- 32% increase, Asian
- 83% increase, Black

DONOR NETWORK WEST



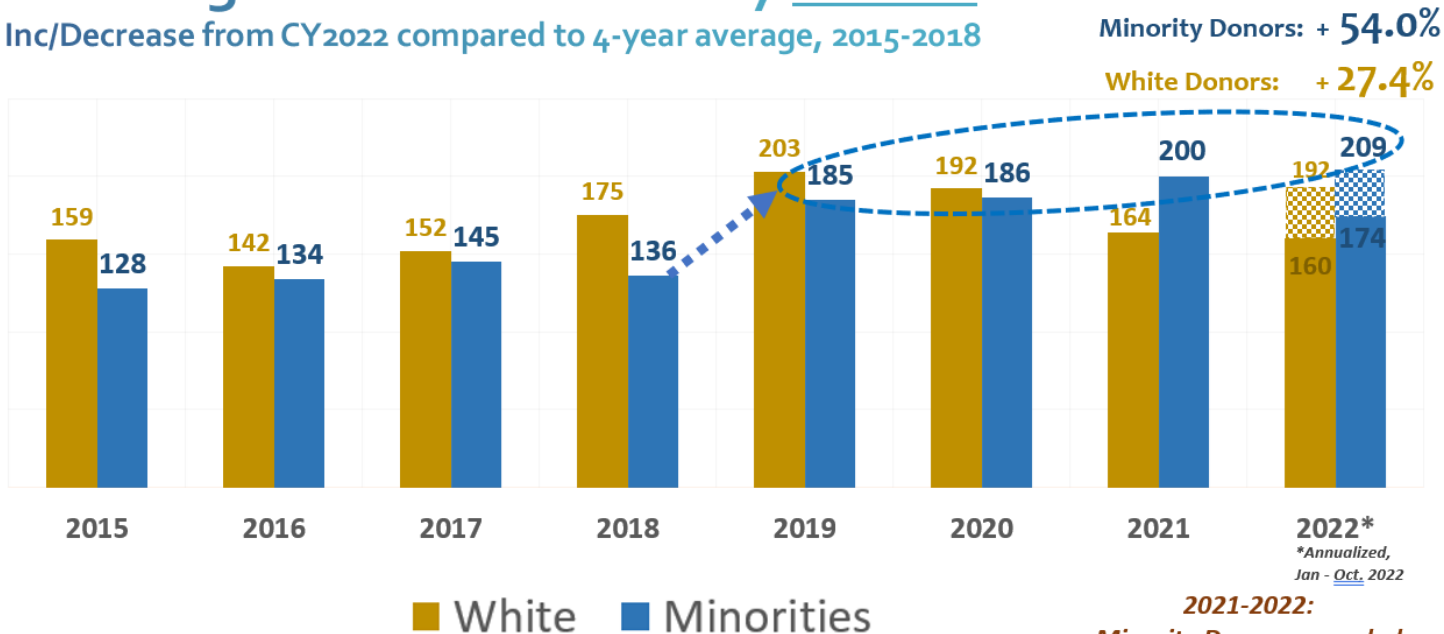
## Medically Suitable Organ Donor Referrals: White vs Minority Inc/Decrease of CY2022 compared to 4-year average, 2015-2018



DONOR NETWORK WEST

## Trending of White vs Minority Donors

Inc/Decrease from CY2022 compared to 4-year average, 2015-2018



DONOR NETWORK WEST

## FOCUS ON SERVING COMMUNITIES OF COLOR

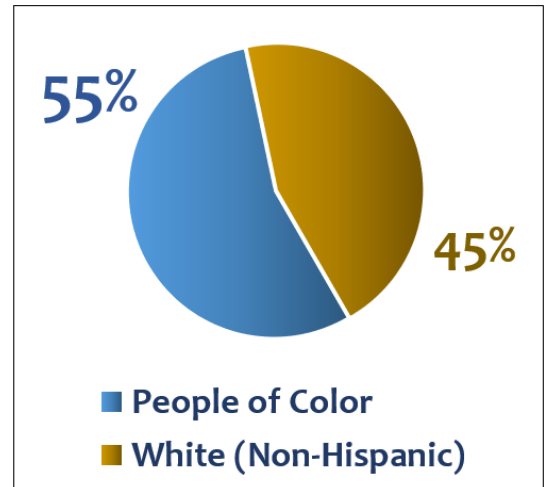
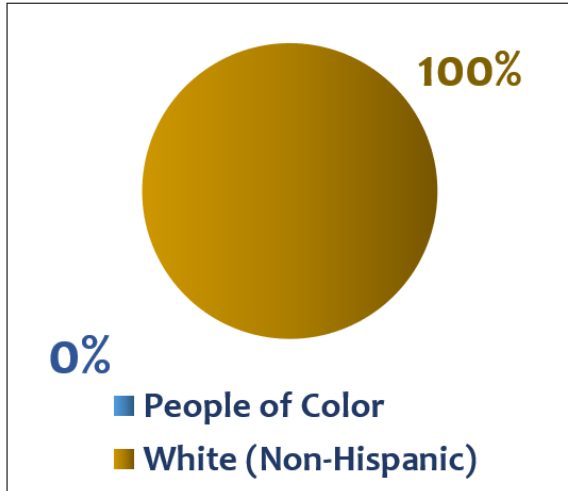
### EXECUTIVE LEADERSHIP, Donor Network West

2016



2022

5-fold Increase in POC Executive Leadership Representation



DONOR NETWORK WEST

## FOCUS ON SERVING COMMUNITIES OF COLOR

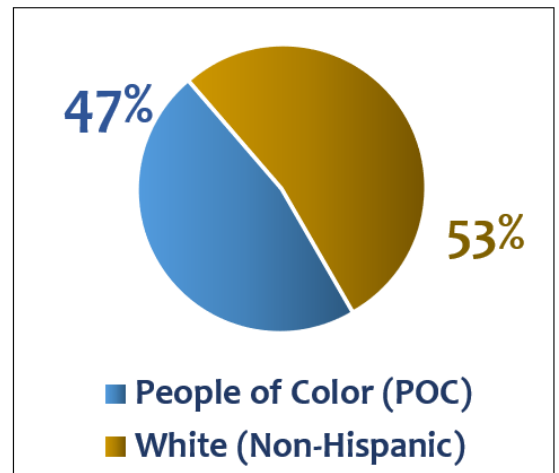
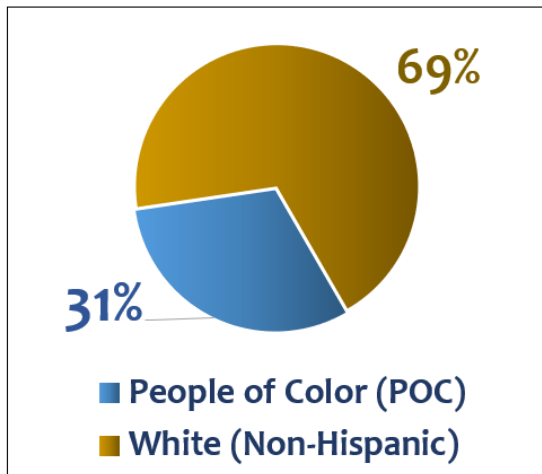
### ALL LEADERSHIP, Donor Network West

2016



2022

48% Increase in POC Leadership Representation

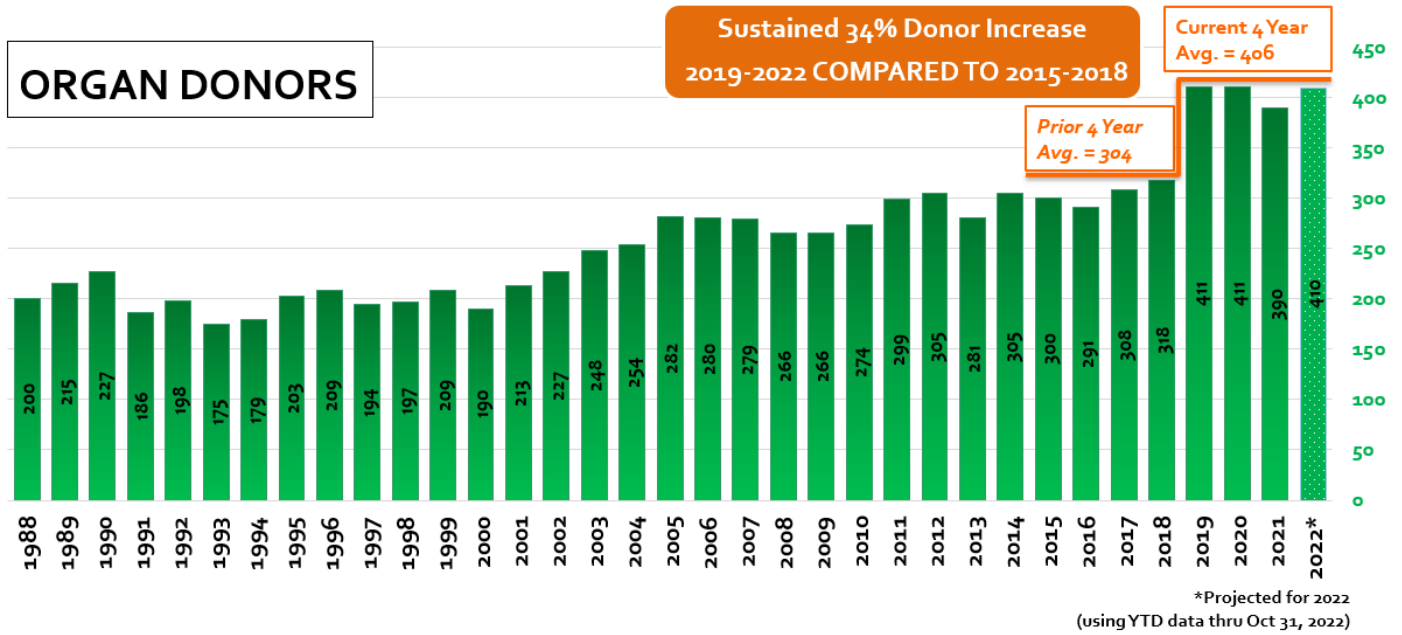


DONOR NETWORK WEST

## DNWest: INCREASING DONATION & SAVING LIVES

### Donation History Since Inception: Organ Donors, 1988 - 2022

#### ORGAN DONORS



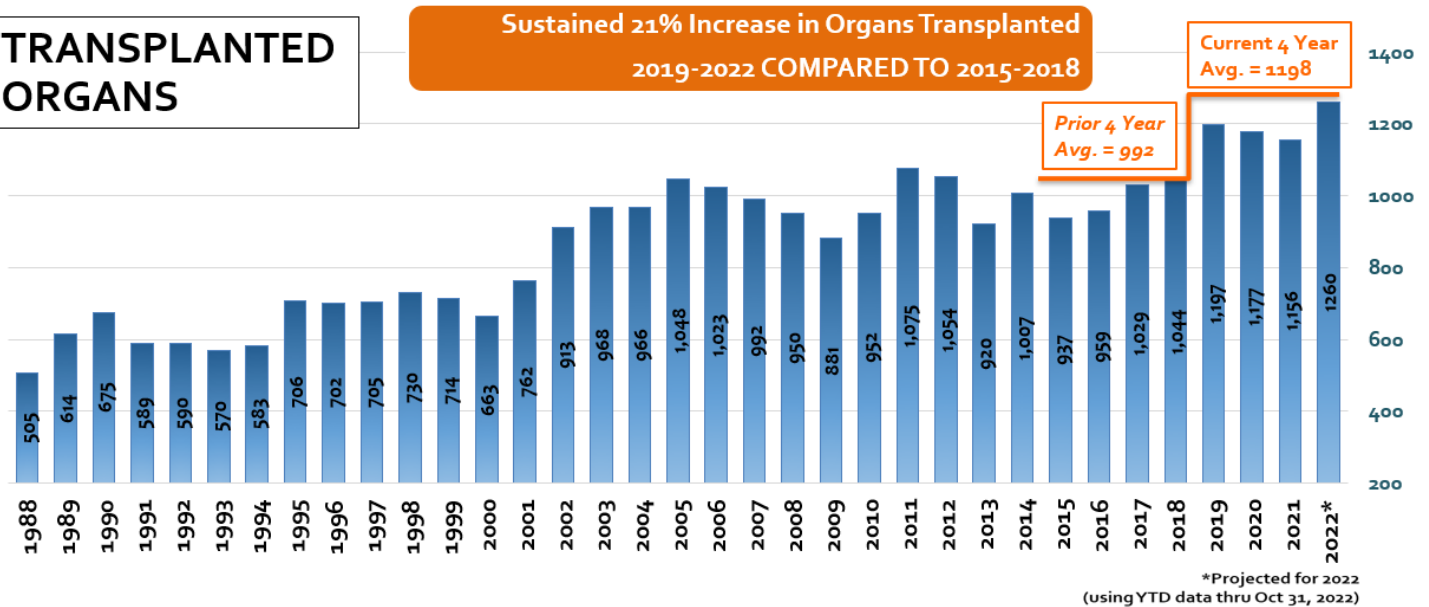
\*OPTN SRTR data, 1988-2022

DONOR NETWORK WEST

## DNWest: INCREASING DONATION & SAVING LIVES

### Donation History Since Inception: Transplanted Organs, 1988 - 2022

#### TRANSPLANTED ORGANS



\*OPTN SRTR data, 1988-2022

DONOR NETWORK WEST

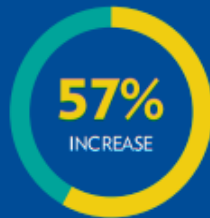
# Our Impact in 2021

## DONOR NETWORK WEST 2021 TOTAL ORGAN & TISSUE DONATION NUMBERS



In 2021, Donor Network West helped more multiethnic donors give the gift of life than ever before.

## 228 MULTIETHNIC ORGAN DONORS



In number of Donors 2018 through 2021

In number of Donors 2018 through 2021

In number of Donors 2018 through 2021

In Authorization for donation 2018 through 2021

## **PUBLIC COMMENTS**

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