Racial Equity in Family Approach for Patients Medically Suitable for Deceased Organ Donation

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OBJECTIVES: To conduct a contemporary analysis of the association between family approach of medically suitable potential organ donors and race/ethnicity.

DESIGN: Retrospective review of data collected prospectively by Organ Procurement Organizations (OPOs).

SETTING: Ten OPOs representing eight regions of the Organ Procurement and Transplantation Network and 26% of all deceased donor organs recovered in the United States.

SUBJECTS: All hospitalized patients on mechanical ventilation and referred to OPOs as potential donors from January 1, 2018, to December 31, 2022.

INTERVENTIONS: None.

MEASUREMENTS AND MAIN RESULTS: OPOs provided data on referral year, race, sex, donor registration status, screening determination, donation medical suitability, donation type (brain death, circulatory death), and family approach. We evaluated factors associated with family approach to discuss donation using descriptive statistics and multivariable logistic models. Of 255,429 total cases, 138,622 (54%) were screened-in for further evaluation, with variation by race/ethnicity (50% White, 60% Black, 69% Hispanic, and 60% Asian). Among those screened-in, 31,253 (23%) were medically suitable for donation, with modest variation by race/ethnicity (22% White, 26% Black, 23% Hispanic, and 21% Asian). Family approach rate by OPOs of medically suitable cases was 94% ($n = 29,315$), which did not vary by race/ethnicity (94% White, 93% Black, 95% Hispanic, and 95% Asian). Family approach by OPOs was lower for circulatory death (95%) vs. brain death (97%) cases but showed minimal differences in approach rate based on race/ethnicity between medically suitable patients with different death pathways. In contrast, donor registration status of medically suitable potential donors was highly variable by race/ethnicity (37% overall; 45% White, 21% Black, 29% Hispanic, and 25% Asian). Multivariable models indicated no significant difference of family approach between White and Black (odds ratio [OR], 1.09; 95% CI, 0.95–1.24) or Asian (OR, 1.23; 95% CI, 0.95–1.60) patients.

CONCLUSIONS: Findings indicate racial equity in OPO family approach rates among patients who were medically suitable for organ donation.

KEYWORDS: donor selection; health inequities; organ donation; organ procurement; race factors

Transplantation remains an extraordinary medical and surgical achievement, extending life and improving the health and well-being for many patients with end-stage organ disease (1–6). More than 750,000 transplants were performed in the United States between 2000 and 2023, with a 100% increase in the number of organ transplants performed annually (23,274 in 2000 vs. 46,630 in 2023) (https://optn.transplant.hrsa.gov/data/view-data-reports/

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KEY POINTS

Question: Does the rate of Organ Procurement Organization (OPO) family approach vary significantly by the potential deceased organ donor's race/ethnicity?

Findings: Family approach rates did not vary by race/ethnicity of the medically suitable potential donor, regardless of death pathway (brain death or circulatory death).

Meaning: Findings support racial equity in the practices of family approach by OPOs, ensuring fairness and inclusivity in organ donation opportunity.

national-data/). This growth in transplantation is largely attributable to a remarkable 173% increase in the number of deceased organ donors during this same time period, due to innovations in donor management, advancements in organ preservation technology, new policies designed to maximize organ donation, expansion of donor eligibility criteria, process improvements along the donation pathway, and an increase in donor registry enrollment (7–11).

Successful transplantation of an organ requires hospitals to fulfill the Centers for Medicare and Medicaid Services (CMS) requirement of reporting all imminent deaths to their regional Organ Procurement Organization (OPO) in a timely manner (9). Upon referral, OPOs screen to identify any absolute clinical contraindications to donation and then, if appropriate, evaluate more thoroughly for donation medical suitability. If medically suitable, organ donation is discussed with the family. The family approach about donation is complex and time-sensitive, necessitating highly trained and compassionate OPO staff who can discuss donation at a time of acute grief and trauma surrounding the death of a family member. If the patient is a registered organ donor, the OPO staff provides donor registry documentation to the family and discusses how the patient's donation decision will be honored. In the absence of donor registration, OPO staff provide support to family members and discuss the opportunity for organ donation. If donation authorization is obtained—either from the patient through registry enrollment or from the family—OPOs then facilitate donor management after death to optimize organ function and the subsequent recovery and placement of organs according to allocation policies of the Organ Procurement and Transplantation Network (OPTN).

Family discussions about donation are a central pillar of the organ donation process. Each OPO has the goal of approaching all families of patients who meet medical suitability criteria for donation. Organ donation authorization is much more likely when the donation discussion has occurred with a highly skilled OPO staff and at the most optimal time for the family (10, 12). This interaction, and the eventual donation decision by the family (in cases where the patient in not a registered donor), is complex and influenced by many cultural, religious, interpersonal, and psychosocial factors.

Prior research suggests racial disparity in family approach rates and opportunities to discuss the option of donation. For instance, in their analysis of donation-eligible deaths at 112 hospitals between 1990 and 1993, Guadagnoli et al (13) found that families of Black patients (n = 814) were approached about organ donation at a statistically lower rate than families of White patients (n = 2202; 67% vs. 79%, respectively). Siminoff et al (14), in interviews with donor and nondonor families whose loved one died between 1994 and 1999, similarly found that Black families (n = 61) of donation-eligible patients were less likely than White families (n = 354) to be given the opportunity by hospital staff to meet with an OPO professional to discuss donation (51% vs. 66%, respectively). Appropriately, these findings raised concerns about racial inequity, especially considering the low organ donation rates among Blacks in the context of their disproportionately higher prevalence of chronic diseases (e.g., hypertension, diabetes) leading to organ transplantation (15).

The previously reported racial disparity in family approach continues to be widely cited and promulgated, including in the 2022 report of the National Academies of Science, Engineering, and Medicine, *Realizing the Promise of Equity in the Organ Transplantation System* (16–18). Given that these studies were based on data collected 2–3 decades ago and at a time when OPO staff were not the primary approachers (federal regulations were changed in 1998 to require potential donor families only be approached by requestors trained by OPOs), our goal was to conduct a more contemporary

analysis of the association between OPO family approach about organ donation and patient race/ethnicity.

METHODS

Data were derived from ten OPOs (OPTN OPO code, OPTN U.S. region) who represented eight OPTN regions and accounted for 26% of all deceased donor organs recovered in the United States: Sierra Donor Services (CAGS, region 5), OneLegacy (CAOP, region 5) Donor Alliance (CORS, region 8), New England Donor Services (MAOB, region 1), Gift of Life Michigan (MIOP, region 10), New Mexico Donor Services (NMOP, region 5), Life Share Oklahoma (OKOP, region 4), Gift of Life Donor Program (PADV, region 2), Tennessee Donor Services (TNDS, region 11), and Life Center Northwest (WALC, region 6).

Upon execution of a research collaboration agreement, each OPO submitted data on all ventilated referrals received from hospitals in their Donation Service Area (DSA) between January 1, 2018, and December 31, 2022, to the first two authors (J.R.R., J.D.S.). One OPO provided data only for years 2020–2022 due to migration of electronic record systems during 2018–2019. Data were reviewed, cleaned, validated, and entered into a single electronic database. Missing data or unusual data patterns were discussed with individual OPOs, as necessary, and either confirmed or corrected based on subsequent review of source material by OPO staff. The Beth Israel Deaconess Medical Center Committee on Clinical Investigations determined that this study did not constitute human subjects research (No. 2023D001023).

The current analysis focuses on the following variables: OPO (anonymized); referral year; race/ethnicity; sex; initial screening determination (i.e., meets or does not meet criteria for further evaluation); medical suitability determination after further evaluation; donation type (i.e., donation after brain death [DBD] or donation after circulatory death [DCD]); donor registry enrollment; and family approach for donation discussion. Additional data were captured and are the focus of a separate analysis, including donation authorization, organ recovery, and transplantation of recovered organs.

Race/ethnicity was categorized as non-Hispanic White, Black, Hispanic, Asian, other (American Indian, Alaskan Native, Native Hawaiian, or Pacific Islander), or unknown. Initial screening determination upon referral and final medical suitability determination were made based upon individual OPO criteria and policies. Donor registration reflected documentation of legally recognized first-person authorization in a state donor registry. For patients younger than 15 years old whose age precluded donor registration opportunity (e.g., too young for a learner's permit or driver's license), donor registration status was coded as "No." Family approach included discussions with family members or legal surrogate decision-makers, either to inform them of the patient's donor registry enrollment and how donation would be facilitated or to seek donation authorization in the absence of donor registration.

We used a multivariable logistic model to evaluate factors associated with family approach among eligible donors. Factors included in this model were patient race/ethnicity (categorized as non-Hispanic White, Black, Hispanic, Asian, and other/unknown), patient sex (male, female), referral year (2018–2022), donation type (DBD, DCD, and unspecified), and donor registration (yes, no/unknown). We also used a second multivariable model with adjustment for OPO (used as a classification variable) to evaluate whether there was variation between OPOs.

RESULTS

Participating OPOs received 255,429 referrals of ventilated children and adults during the study period. Referred cases were predominantly male (n = 150,904, 59.1%) and non-Hispanic White (n = 168,660, 66.0%) (Black, n = 31,103, 12.2%; Hispanic, n = 33,577, 13.1%; Asian, n = 9,911, 3.9%; and other/unknown, n = 12,178, 4.8%). Other/unknown cases included those originally classified as American Indian or Alaska Native (n = 5759), Native Hawaiian or other Pacific Islander (n = 318), other (n = 94), or unknown (n = 6007). Excluding the one OPO for whom 2018–2019 data were unavailable, there was a 41.4% increase in ventilated referrals from 2018 (n = 37,613) to 2022 (n = 53,185). Donor registry enrollment and death pathway are sometimes unknown at time of referral and initial screening. However, among cases deemed medically suitable for donation, 11,625 (37.2%) were registered donors (61.3% not registered, 1.5% with unknown registry status) and 14,453 (46.2%) were DBD cases (33.7% DCD, 20.1% unspecified).

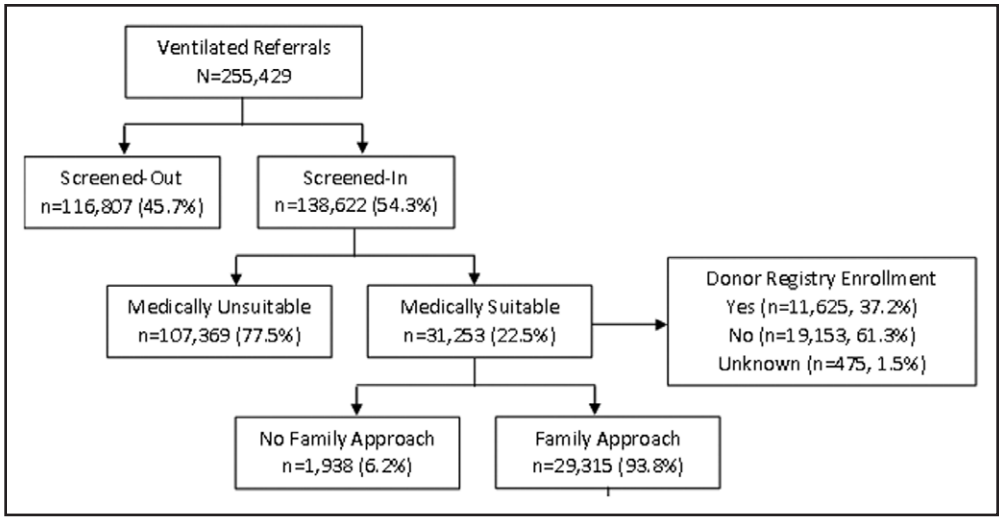

Figure 1. Flow of ventilated referrals through family approach, 2018–2022.

Figure 1 summarizes the number and percentage of cases from referral to family approach. Of the 255,429 referred and screened cases, 138,622 (54.3%) were "screened-in" for further evaluation. Of those cases screened-in, 31,253 (22.5%) were deemed medically suitable for donation upon further evaluation, resulting in 29,315 family approaches (93.8% of medically suitable cases). Family approach rates among the ten OPOs ranged from 88.0% to 98.2%.

Table 1 displays descriptive data (i.e., number and percentage) of cases from referral to OPO family approach, by race/ethnicity. Hispanic patients (68.7%) had the highest screened-in rate, whereas non-Hispanic White patients had the lowest (50.3%); Black patients (26.1%) had the highest likelihood of being medically suitable for donation, while those with other/unknown race/ethnicity (14.9%) had the lowest; and, among those medically suitable for donation, non-Hispanic White patients (45.2%) had the highest rate of donor registry enrollment, and Black patients had the lowest (21.4%). There was considerably less variability for family approach rates, with the proportion of medically suitable patients with a family approach being higher than 90% across all race/ethnicity groups.

Of the 1938 patients who were medically suitable for donation but for whom the family was not approached, 433 (22.3%) were registered organ donors. Nonapproach of families for registered donors was more likely for non-Hispanic White patients (28%) than for non-White patients (13% overall; Black, 13%; Hispanic, 12%; and Asian, 13%).

The adjusted likelihood of family approach based on a multivariable logistic model is summarized in **Table 2**. Relative to non-Hispanic White patients, Black and Asian patients had no significant difference in the adjusted likelihood of family approach (adjusted odds ratio [AOR], 1.09; 95% CI, 0.95–1.24

TABLE 1.
Number (Percentage) of Cases From Referral to Family Approach, by Race/Ethnicity (*n* = 255,429)

Organ Donation Step	White	Black	Hispanic	Asian	Other/ Unknown	Total
Step 1: Referred	168,660	31,103	33,577	9,911	12,178	255,429
Step 2: Screened-in, yes	84,813 (50.3)	18,559 (59.7)	23,072 (68.7)	5,930 (59.8)	6,248 (51.3)	138,622 (54.3)
Step 3: Medically suitable, yes	18,949 (22.3)	4,848 (26.1)	5,260 (22.8)	1,268 (21.4)	928 (14.9)	31,253 (22.5)
Registry enrollment, yes	8,565 (45.2)	1,037 (21.4)	1,503 (28.6)	319 (25.2)	201 (21.7)	11,625 (37.2)
Step 4: Family approach, yes	17,754 (93.7)	4,504 (92.9)	5,017 (95.4)	1,198 (94.5)	842 (90.7)	29,315 (93.8)

Data in each row are the number (%) of cases from the prior step within each race/ethnicity column.

TABLE 2.
Multivariable Model for Adjusted Likelihood of Family Approach Among Medically Suitable Potential Deceased Donors

Variable	Level	OR (95% CI)
Race/ethnicity	Non-Hispanic White	Reference
	Black	1.09 (0.95–1.24)
	Hispanic	1.44 (1.24–1.67)
	Asian	1.23 (0.95–1.60)
	Other/unknown	0.60 (0.48–0.76)
Referral year	2018	Reference
	2019	0.84 (0.71–1.00)
	2020	1.30 (1.10–1.53)
	2021	1.43 (1.22–1.68)
	2022	1.51 (1.29–1.76)
Donation type	Donation after brain death	1.80 (1.59–2.04)
	Donation after circulatory death	Reference
	Unknown	0.33 (0.29–0.37)
Sex	Male	Reference
	Female	1.06 (0.96–1.16)
Donor registry enrollment	No/unknown	Reference
	Yes	2.33 (2.08–2.61)

OR = odds ratio.
$n = 31{,}228$ ($n = 4$ missing data not included); concordance index of model = 0.71.

and AOR, 1.23; 95% CI, 0.95–1.24, respectively), while Hispanic patients had higher likelihood (AOR, 1.44; 95% CI, 1.24–1.67) and other/unknown patients had lower likelihood of a family approach (AOR, 0.60; 95% CI, 0.48–0.76). Relative to 2018, there was an increased likelihood of family approach in subsequent years, including a 51% higher adjusted likelihood, in 2022 (AOR, 1.51; 95% CI, 1.29–1.76). The unadjusted family approach rate by year was 93.7% in 2018, 92.7% in 2019, 93.7% in 2020, 94.2% in 2021, and 95.0% in 2022. DBD patients had a higher likelihood of family approach relative to DCD patients (AOR, 1.80; 95% CI, 1.59–2.04). There was no difference in likelihood of family approach by patient sex; however, patients who were registered donors had more than two-fold likelihood of family approach (AOR, 2.33; 95% CI, 2.08–2.61). Results of the multivariable logistic model including OPO as an explanatory variable indicated that there was statistically significant variation in the likelihood of approach by OPO ($p < 0.001$) (**Table 3** for family approach rates by anonymized OPO and patient race/ethnicity). All other factors associated with statistically significant likelihood of approach remained consistent in this model with the exception that Hispanic ethnicity was no longer associated with increased likelihood of approach. Additionally, the OPO × race/ethnicity interaction was not statistically significant ($p = 0.14$).

DISCUSSION

In this national study of 255,429 hospital referrals to ten OPOs over a recent 5-year period, we found that the family approach rate is high (94%) among donation-eligible patients and similar across the potential donor's race/ethnicity, thus ensuring equitable access to organ donation opportunity. This family approach rate for patients medically suitable for donation is substantially higher than previously reported (13, 14) and highlights the efforts of skilled OPO staff who work with families at a time of heightened grief and loss to facilitate an informed choice about organ donation. Our finding that families of Black, Hispanic, and Asian patients were approached at rates equivalent to, or higher than, that of non-Hispanic White patients differs sharply from findings published decades ago and which continue to be cited as evidence of racial bias in family opportunity to donate organs of a deceased family member (13, 14, 16–18).

The disparate findings between those earlier studies and ours likely reflect the different eras in which they were conducted. For instance, Guadagnoli et al (13) and Siminoff et al (14) reported data collected 2–3 decades ago and in an era when systematic efforts to evaluate organ donation eligibility among dying patients were largely nonexistent. In that earlier era, organ donation was not always discussed with families of donation-eligible patients and, if discussions did occur, they were often initiated by untrained hospital staff (12, 19). Also, in many hospitals OPO-led family approaches were permitted only upon invitation by hospital staff. Racial bias, among other factors, certainly may have contributed to disparities in family approach rates at that time. The "Donation Rule" implemented in 1998 by CMS ushered in a new donation era by requiring hospitals to report in a timely manner all imminent deaths to their

TABLE 3.
Family Approach Rate (%) by Organ Procurement Organization and Patient Race/Ethnicity

Organ Procurement Organization	White	Black	Hispanic	Asian	Other/Unknown	Total
1	95.4	93.8	95.1	96.2	100.0	95.0
2	94.1	90.8	94.1	91.2	87.8	93.1
3	98.6	98.3	96.3	98.0	97.2	98.2
4	86.7	86.9	95.1	96.2	92.8	88.0
5	90.4	88.4	92.1	85.6	84.4	89.6
6	89.6	84.8	85.5	95.0	83.3	88.4
7	92.1	92.4	91.9	85.3	100.0	92.1
8	93.8	94.6	92.9	94.4	91.2	93.8
9	94.1	96.4	94.6	100.0	93.5	94.3
10	97.3	97.8	97.7	97.7	100.0	97.6

regional OPO and specifying that only OPO staff or OPO trained requestors could approach families about donation (9). Thus, data reported by Guadagnoli et al (13) and Siminoff et al (14) do not reflect contemporary OPO practices of the past 2 decades, were not inclusive of other racial/ethnic minorities (e.g., Hispanic, Asian), and comprised very small sample sizes, important limitations that were overcome by our more contemporary analysis.

Also running counter to the persistent narrative of racial bias in organ donation opportunity is our finding that Black, Hispanic, and Asian patients were more likely than non-Hispanic White patients to be screened-in for further donation evaluation upon referral to the OPO. Importantly, of those screened-in, Black patients were more likely than patients in other race/ethnicity categories to meet medical criteria for donation eligibility. More recently, Levan et al (20) found that Black and other non-Black/non-White patients had lower odds of a family approach than White patients. However, a major limitation of prior studies, including the more recent study by Levan et al (20), was calculating the family approach rate using referred patients as the denominator, without considering the medical suitability of those cases for donation (13, 14, 20). Omitting the complex medical suitability evaluation process when examining family approach rates may contribute to spurious findings of racial disparity in family approach. For obvious ethical and psychologic reasons, OPOs should not approach grieving families to discuss donation if their loved one is not actually medically suitable for donation.

We found higher rates of family approach among Hispanic, donation-eligible patients. This finding is likely due to one OPO, with the second highest family approach rate, accounting for 48% of Hispanic patients in our sample. Family approach rates were also higher for DBD cases compared with DCD cases, although this difference was proportionally small (96.7% vs. 94.5%). DCD cases present unique clinical, technical, ethical, and decision-making challenges for OPO staff and families, which may affect the initiation of—or delay the timing of—donation discussions with families. In some instances, a DCD case may not clinically progress in a manner that ultimately allows for donation to occur and, consequently, the family is appropriately not approached about organ donation. We were not able to discern how frequently this occurred in our current sample. Nevertheless, considering the substantial increase in donation-eligible DCD cases during the study period (28% in 2018 to 42% in 2022), targeted efforts to improve education, streamline processes, and ensure ethical considerations are carefully managed, all while supporting families through the donation decision-making process, should remain a priority of OPOs.

This study corroborates similar findings highlighting the role of donor registration in the likelihood of family approach (20). Patients with known donor registration, regardless of race/ethnicity, had a significantly higher chance of a family approach. There are

times when a family is resistant to discussing donation with OPO staff when the patient's donation intention is unknown. Additionally, hospital staff may be less willing to support a patient hemodynamically when the patient is not a registered donor or donor registration status is unknown. Thus, our finding underscores the importance of the patient's own prior authorization in facilitating organ donation discussions. Notably, the donor registration rate (37.2%) among those medically suitable for donation was significantly lower than the 50% observed in the general population (21), which is commonly observed across OPOs. This difference in registration rates between the general population and the medically eligible potential donor population is due to the fact that age older than 50 years old, male sex, minority race/ethnicity, and lower socioeconomic status are all associated with lower donor registration rates in the general population (21) and are characteristics over-represented among those who are medically eligible potential donors. Programmatic efforts to increase donor registration rates in these subpopulations remain critically important.

While representing a small minority, 1938 families (or 6.2% of those for whom a patient was medically suitable for donation) were not approached, including 433 families of registered donors. There are several plausible explanations for a non-approach, including COVID pandemic restrictions during this study period impacting OPO staff ability to connect with families, untimely hospital referral, patient identity is unknown, family members are not found or are unresponsive to contact efforts, the medical examiner may not release the case for donation, and the patient may suffer a cardiac arrest precluding a family conversation, among others. Nevertheless, this represents an opportunity for OPO process improvement to maximize family approach rates, especially when donor registration is known.

Findings from this study should be interpreted in light of its relative strengths and limitations. Data were gathered across a 5-year period from ten OPOs representing eight of the 11 OPTN regions and accounting for more than one-quarter of all deceased donors in the United States, making this study the largest and most geographically representative ever undertaken to examine family approach rates. Also, we considered family approach rates in the context of initial screening upon referral, medical suitability determination, and donation type (DBD, DCD), better reflecting the pathway from hospital referral to family approach than in prior studies. Notwithstanding these notable strengths, important limitations of the study must be acknowledged. For instance, while representing 26% of all deceased donors in the United States, our OPO cohort may not be representative of all OPOs; therefore, we do not know whether our finding of racial equity in family approach can be generalized to other OPOs not part of this analysis. We did not have data on the reasons why referred patients were medically screened-out or deemed ineligible for donation. There is likely some variability across OPOs in the criteria used to determine medical suitability for donation and, therefore, it is possible that there were more donation-eligible patients within the population we studied. We also did not capture reasons why families of donation-eligible patients were not approached or details about the approach itself, which may shed light on both the complexities of family approach (e.g., timing, clinical factors, and logistics) and process improvement opportunities. Other covariates (e.g., age, death mechanism) potentially relevant to family approach rates were also not captured. While each OPO recruits a racially and linguistically diverse workforce that is representative of the population served within their respective DSA, we did not capture OPO requestor race/ethnicity to examine its association with family approach rate. Finally, our study timeframe (2018–2022) includes the COVID pandemic, which may have affected processes in ways that adversely impacted family approaches and which were not examined in this study (22, 23). However, despite the many logistical challenges confronted by OPOs, the proportion of family approaches increased during the COVID pandemic.

In conclusion, approaching families and providing the opportunity for organ donation when medically suitable remains a central responsibility of OPOs. This requires highly skilled OPO staff who can effectively balance the emotional needs of the grieving family, the complex array of clinical and logistical factors, and the optimal timing for donation discussion. Our findings indicate that OPOs engage families in organ donation discussions at a rate much higher than previously identified. Furthermore, we found racial equity in family approach rates, thus ensuring fairness and inclusivity in these critical conversations and in

opportunity to make an informed choice about organ donation.

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8 *Gift of Life Michigan, Ann Arbor, MI.*
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