



**SB574 - Organ and Tissue Donation Awareness Fund - Annual Funding and Extension  
FAVORABLE**

February 22, 2022

Hon. Shane E. Pendergrass  
Chairman, Health and Government Operations Committee  
241 House Office Building  
6 Bladen Street  
Annapolis, MD 21401

Dear Chairman Pendergrass, Vice-Chair Pena-Melnyk, and Committee Members,

On behalf of The Living Legacy Foundation of Maryland (The LLF) and the more than 3,600 Marylanders awaiting a life-saving organ transplant, thank you for your continued support of organ and tissue donation. The LLF is privileged to work collaboratively with Maryland hospitals, transplant centers, the Office of the Chief Medical Examiner, and funeral homes to facilitate organ and tissue donation. We also work collaboratively with Donate Life Maryland, with whom we partner for donation related public education initiatives. Every day, we have the honor of working with families, who at a time of tremendous loss, help others through the gift of donation. Without the incredible support of the Maryland legislature, we would be unable to achieve the success we have in saving and enhancing lives through donation.

The LLF serves as the Organ Procurement Organization (OPO) for most of the state of Maryland. As one of 57 OPOs certified by the Centers for Medicare and Medicaid Services (CMS), and a member of the Organ Procurement and Transplantation Network (OPTN), The LLF coordinates the donation process for all Maryland counties, with the exception of Montgomery, Prince George, and Charles Counties. These counties are served by our colleague OPO, the Washington Regional Transplant Community. When a Maryland hospital recognizes an individual has suffered a non-recoverable injury or has died, their staff contacts The LLF or WRTC. We then evaluate the potential donor, check local and national registries for donor designation status, discuss donation with family members, and arrange the recovery and transport of donated organs. We also provide extensive bereavement support for donor families in the years following their loved one's donation.

On behalf of The LLF, we offer our full support for SB574. Maintaining the framework and funding that contributes to our community-based education initiatives is critical to ensuring that Marylanders in need receive life-saving and life-enhancing transplants.



OPOs that offer community outreach programs are important vehicles for educating the public about the importance of organ, eye, and tissue donation. Our organization would like to highlight one initiative in particular, which illustrates the importance of having adequate funding and resources.

The LLF, with the support of Donate Life Maryland, identifies priority areas that focus on health disparities and improving relationships among the Maryland community. To reach more people in a more authentic way, The LLF wanted to hear thoughts, experiences, and opinions about donation directly from community members.

In 2016, The LLF has created a grassroots initiative, The Decision Project (TDP). Through focus groups, community sponsorships, and direct relationships (that come from funding through the organ and tissue and awareness fund), we hope to empower people to make an educated and inspired decision about donation.

The LLF collaborated with community trusted faith based, healthcare, youth, and recreational organizations to share our findings and discuss concerns surrounding donation and transplantation. Three focus groups were conducted over the course of 18 months with community members, to identify attitudes and barriers towards donation. Residents shared many perspectives during these focus groups; primarily, their distrust of the medical community and their beliefs that they were too sick to donate.

As a result of the findings of the focus groups, The LLF prioritized the following activities:

- Establish a strong community presence to give back to those in need
- Investigate and dispel root causes of donation myths and misconceptions
- Share personal testimony from transplant recipients and family members of donors
- Provide reliable educational resources throughout the area

We have found that each activity is fundamental to increasing the donor designation and authorization rates. It also became evident that each neighborhood requires unique mechanisms to overcome these barriers, and that there is no “one size fits all” approach.



While The LLF makes no claim that correlation means causation, there have been significant increases in both donor designation (+500%) and authorization rates (+71%) within the priority zip code since implementation of The Decision Project from 2016-2019. The LLF continues to analyze these trends. Additionally, this initiative has linked services to those most in need in these communities, including fresh food accessibility, COVID-19 screenings and vaccines, accessibility of school supplies for children, and more. It is a privilege to carry out our mission and serve these communities that have traditionally struggled with access to resources.

Thank you for your consideration. We welcome the opportunity to answer any questions you might have or provide additional information.

Sincerely,

A handwritten signature in black ink that reads "Karen Kennedy".

Karen Kennedy  
Vice President of External Affairs and Education  
The Living Legacy Foundation of MD

A handwritten signature in black ink that reads "Ieesha Johnson".

Ieesha Johnson  
Director of Community Outreach  
The Living Legacy Foundation of MD



## MARYLAND COMMUNITY OUTREACH COVERAGE

- Region 1
- Region 2
- Region 3
- WTRC

Each region includes MVA's, high schools, community partners, and workplace partners

**Contact Information:**

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**The Decision Project**

The Decision Project (TDP) is a grassroots initiative created by The Living Legacy Foundation of Maryland (The LLF) that empowers people in underserved communities to make an informed and inspired decision about organ, eye, and tissue donation. TDP focuses on areas with low rates of designated organ donors to:

- Educate about the crucial need for organ, eye, and tissue donors
- Establish trust in the donation process by dispelling myths and misconceptions
- Support communities we serve through partnerships and sponsorships

**Background**

In 2016, The LLF identified Baltimore's 21215 community as having one of Maryland's lowest donor designation rates\*, with only 9% of the community designating themselves as organ donors. Of particular concern, the community also had the largest number of residents waiting on a transplant list for a life-saving organ. Baltimore's 21215 zip code is a predominately impoverished African American community that experiences increased crime rates and food insecurity.

The LLF collaborated with community trusted faith based, healthcare, youth, and recreational organizations to share our findings and discuss concerns surrounding donation and transplantation. Three focus groups were conducted over the course of 18 months with community members, to identify attitudes and barriers towards donation. Residents shared many perspectives during these focus groups; primarily, their distrust of the medical community and their beliefs that they were too sick to donate.

As a result of the findings of the focus groups, The LLF prioritized the following activities:

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We have found that each activity is fundamental to increasing the donor designation and authorization rates\*. It also became evident that each neighborhood requires unique mechanisms to overcome these barriers, and that there is no "one size fits all" approach.

**Results**

While The LLF makes no claim that correlation means causation, there have been significant increases in both donor designation (+500%) and authorization rates (+71%) within the priority zip code since the implementation of The Decision Project from 2016-2019. The LLF continues

to analyze these trends. Additionally, this initiative has linked services to those most in need in these communities, including fresh food accessibility, COVID-19 screenings and vaccines, accessibility of school supplies for children, and more. It is a privilege to carry out our mission and serve these communities that have traditionally struggled with access to resources.

### **Challenges**

Due to the COVID-19 pandemic, the number of opportunities to safely have in-person events has been substantially reduced. The LLF has since transferred its efforts to online platforms, which understandably may not be accessible to those in underserved communities.

### **Goals**

The continued success of TDP in 21215 has led The LLF to expand its efforts into Baltimore City's 21205 and 21213 (East Baltimore) and Howard County's 21044 and 21045 zip codes. We hope to determine the unique needs of these communities and increase donor designation.

### **Key Community Partnerships**

Danielle McCray, Baltimore City Councilwoman	James Torrence, Baltimore City Councilman
Isaac "Yitzy" Schleifer, Baltimore City Councilman	Leon Pinkett, Executive Director Baltimore Arts Realty Corp. and former Baltimore City Councilman
Dr. Macey Levan, The Johns Hopkins University	Dr. Tanjala Purnell, The Johns Hopkins University
Park Heights Health Alliance	The Maryland Food Bank
Men's & Families Center	NAACP, Howard County Chapter
National Kidney Foundation of Maryland	Northwest Faith Based Partnership
Park Heights Saints Youth Football Organization	Safe Streets Park Heights
Sinai Hospital of Baltimore Department of Population Health	Somebody Cares Baltimore
Amerigroup	Pastor Kevin English Open Bible Church

### **Definitions:**

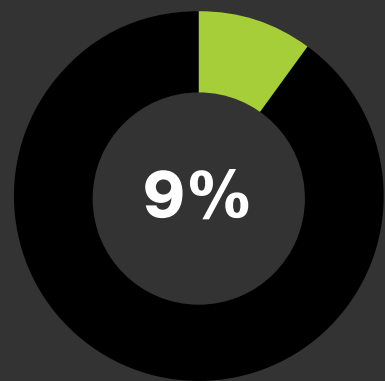
\*Donor Designation Rate - The rate at which individuals join the state donor registry as a percentage of all driver's licenses and ID cards issued within a specific period of time. (Donate Life America)

\*Authorization Rate - The number of authorizations for organ donation, divided by the number of approaches made for potential organ donors. (The Organ Donation Alliance)

# the decision project

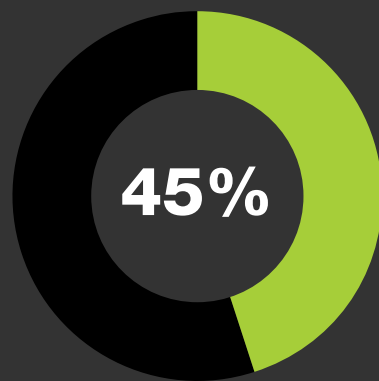
AN EXPLORATORY  
LOOK INTO  
THE DATA

## 2016



**Donor Designation Rate**

Designation for priority zip code in 2016, before concentrated outreach through The Decision Project



**Authorization Rate**

Authorization for priority zip code in 2016, before concentrated outreach through The Decision Project

## enter the decision project

The Decision Project is a data-focused, grassroots initiative that empowers people in some of the most underserved, lowest donor designated areas to make an educated and inspired decision about organ, eye, and tissue donation, as well as share that decision with their family. Additionally, this campaign seeks to increase our OPO's.

### Since 2016, The LLF has...

- Sponsored a "Summers in the 7th" block party in 2018 and 2019.
- Hosted an annual Gospel Fest.
- Sponsored children and adults through youth groups, community gardens, food drops, school supply drives, health screenings, preventive health events, and more.
- Participated in over 50+ events.
- Created city council partnerships.
- Obtained a grant from the local food bank to assist with community service efforts in the area.
- Supported The Decision Project to become a national campaign, expanding into other states to come.



## where do we stand now?

## 2019

While The LLF makes no claims that correlation means causation, it's clear that there have been significant increases in both designation (+500%) and authorization rates (+71%) within the priority zip code since the implementation of The Decision Project, from 2016-2019. The LLF continues to analyze these trends.

# ↑ 500%

**Donor Designation Rate**

# ↑ 71%

**Authorization Rate**