

**The LLF Testimony for SB0574F\_IJ KK\_Final.pdf**

Uploaded by: leesha Johnson

Position: FAV



**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.

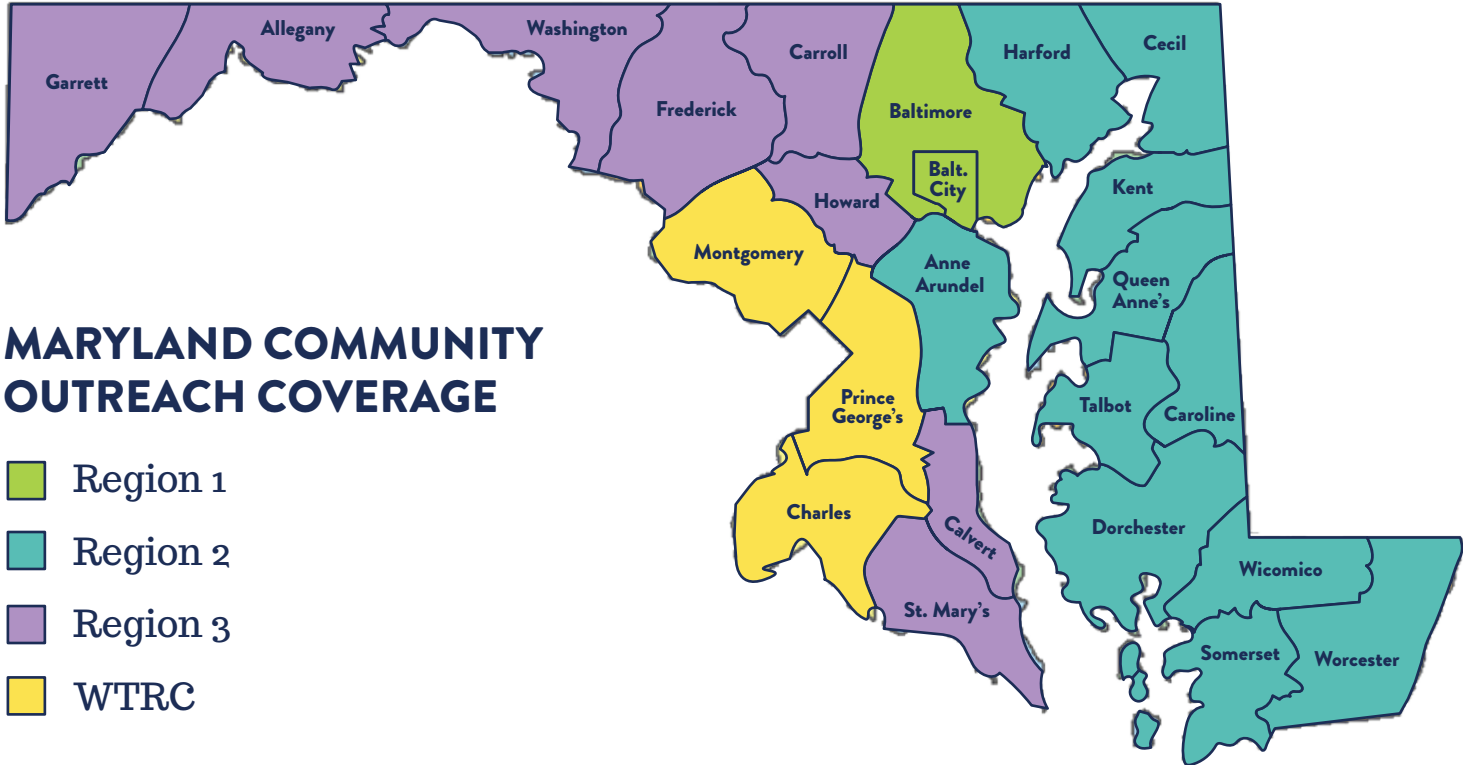
Sincerely,

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:**

Ieesha Johnson, Director, Community Outreach

Email: [ijohnson@TheLLF.org](mailto:ijohnson@TheLLF.org)

**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:

- 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.

**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:**

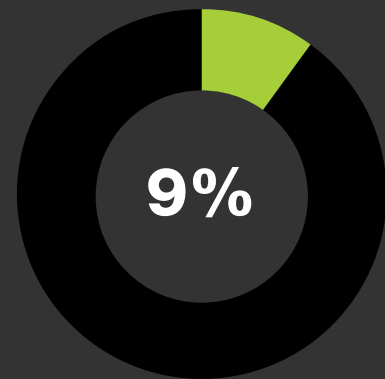
\*Donor Designation Rate - The rate at which individuals join the state donor registry as a percentage of all driver's licenses and ID cards issued within a specific period of time. (Donate Life America)

\*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

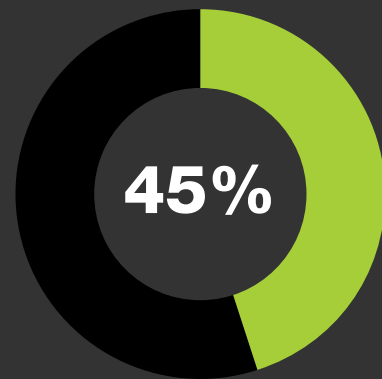
AN EXPLORATORY  
LOOK INTO  
THE DATA

## 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**



**DLM Testimony\_SB574.pdf**

Uploaded by: Lisa Spicknall

Position: FAV



1730 Twin Springs Road  
Suite 200  
Baltimore, MD 21227  
1.866.MD.DONOR

**SB 574 Organ and Tissue Donation Awareness Fund  
Annual Funding and Extension  
FAVORABLE**

February 23, 2022

Hon. Guy Guzzone  
Chair, Budget and Taxation Committee  
3 West, Miller Senate Office Building  
Annapolis, Maryland 21401

Dear Chairman Guzzone, Vice Chair Rosapepe, and Committee Members,

On behalf of Donate Life Maryland and the more than 3,600 Marylanders awaiting a life-saving organ transplant, thank you for your continued support of organ and tissue donation. Our mission is to save and enhance lives by registering organ, eye and tissue donors, providing public education and awareness about organ, eye and tissue donation in Maryland. With our vision to ensure every Marylander can make an educated decision about organ, eye and tissue donation.

As the state-authorized nonprofit responsible for managing the Maryland donor registry, we are honored to work with and support Maryland's two federally designated organ procurement organizations, the Washington Regional Transplant Community and the Living Legacy Foundation.

SB 574 will provide continuation of the necessary funding to ensure Marylanders continue to register as organ, eye and tissue donors, while helping to maintain the current organ donor registry of over 2.6 million Marylanders. This bill will ensure there is no interruption in the promotion of public education and awareness regarding organ, eye and tissue donation, while also maintaining the donor registry. By continuing this funding, Donate Life Maryland, in conjunction with The Living Legacy Foundation and Washington Regional Transplant Community, will ensure that every Marylander is able to make an educated decision about organ, eye and tissue donation and register as a donor.

Since our inception in 2009, Donate Life Maryland has provided much needed outreach and education on the importance of this cause. Launched in 2009, the Maryland Donor Registry securely and confidentially contains the names of those over 2.6 million Marylanders who have registered indicating their desire to be organ, eye and tissue donor. In partnership with the Maryland Department of Transportation Motor Vehicle Administration, Donate Life Maryland not only trains new employees on the importance of organ, eye, and tissue donation, but also ensures the motor vehicle administration has sufficient brochures and handouts to answer any questions a new registrant may have.

**What can YOU make possible? Register TODAY to be an organ, eye and tissue donor!  
To become a donor visit: [register.donatelifemaryland.org](http://register.donatelifemaryland.org)**



1730 Twin Springs Road  
Suite 200  
Baltimore, MD 21227  
1.866.MD.DONOR

In 2016, Donate Life Maryland partnered with The Living Legacy Foundation on The Decision Project. This data driven grassroots initiative identifies priority areas that focus on health disparities and improving relationships among the Maryland community. By working to target these priority areas, Donate Life Maryland and LLF ensures that those priority areas are supported and educated on organ, eye and tissue donation.

As Donate Life Maryland continues to work to raise awareness of organ, eye and tissue donation, we also work to save lives. Each organ donor can save up to 8 lives, and up to 75 lives through tissue donation. These incredible gifts restore health, extend life, and heal many people each year.

By passing SB574 Donate Life Maryland will be able to continue donor education and awareness, increase donor designations, foster lasting relationships, identify barriers, and continue to save lives by registering donors.

We sincerely appreciate the legislature's ongoing support of our efforts and your role in helping us save lives and honor donors, their families, and the very grateful recipients whose lives are changed through organ and tissue donation.

Sincerely,

A handwritten signature in black ink that reads "Lisa M. Spicknall".

Lisa Spicknall  
Executive Director  
Donate Life Maryland

**What can YOU make possible? Register TODAY to be an organ, eye and tissue donor!  
To become a donor visit: [register.donatelifemaryland.org](http://register.donatelifemaryland.org)**



# Saving and enhancing lives by registering organ, eye and tissue donors.

We are the state-authorized nonprofit organization responsible for managing the Maryland Donor Registry.

Established in 2007, DLM works closely with the two federally designated nonprofit organ procurement organizations serving Maryland, The Living Legacy Foundation of Maryland (LLF) and the Washington Regional Transplant Community (WRTC).

In addition to managing and operating the Maryland Donor Registry, DLM, in partnership with The LLF and WRTC, helps spread the word about organ, eye and tissue donation and how to register as a donor in Maryland.

## VISION

**EVERY** Marylander can make an educated decision about organ, eye and tissue donation and registering as a donor.

## Quality Commitment

In collaboration with our OPO partners, we strive to further our mission of saving and enhancing lives by registering organ, eye and tissue donors.

**Registered over 2.2 Million Donors.**

**Lobbied for numerous lifesaving laws in Maryland.**

**Provides outreach and education on the importance of organ, eye and tissue donation.**

**Since 2009**

**Over 3,000 Marylanders are currently waiting for a life-saving transplant.**

[www.donatelifemaryland.org](http://www.donatelifemaryland.org)



[info@donatelifemaryland.org](mailto:info@donatelifemaryland.org)

**Tim Heely SB574 testimony.pdf**

Uploaded by: Tim Heely

Position: FAV

Mr. Tim Heely  
21652 Joe Hazel Road  
Leonardtown, MD 20650

**SB 574 Organ and Tissue Donation Awareness Fund  
Annual Funding and Extension  
FAVORABLE**

Hon. Guy Guzzone  
Chair, Budget and Taxation Committee  
3 West, Miller Senate Office Building  
Annapolis, Maryland 21401

Dear Chairman Guzzone, Vice Chair Rosapepe, and Committee Members,

Good afternoon. I am Tim Heely – I am a resident of St. Mary’s County, a retired Navy Rear Admiral, a board member of Donate Life Maryland, a father of three children and a grandfather of three - and a recipient of a heart transplant in 2013.

After graduating from the Naval Academy I spent 33 years in the Navy flying jet fighters from aircraft carriers based in California and Japan, with my final ten years in the Navy being stationed at Naval Air Station Patuxent River Maryland.

When I retired in 2008 I was contemplating where my wife, Cherie and I would live. I was informed by Cherie, a Talbot County native, that I should stop worrying about it – we were going to live in Maryland.

And she was right.

Life was good, I had a nice job in Rosslyn, Virginia to which I commuted daily.

Then, in 2011, I started experiencing shortness of breath and a lack of stamina. Being a fighter pilot, the doctor was the last person I wanted to see – but Cherie drove me to the hospital, I was diagnosed as having had a heart attack, and treated with a couple stents and then eventually an artificial heart, or Left Ventricular Assist Device, which kept me alive for two years until I was able to get a heart transplant.

I was lucky – I was healthy enough that I was able to function near 100% while awaiting my heart, and so I was not deemed a priority for the few available hearts. But after two years, my luck began to run out and the Device began to shred my blood cells and it was my turn for the next available heart.

Since then I have run several companies, serve on a half dozen boards, have given away our daughter in marriage and welcomed a daughter-in-law to the family and have met my three grandchildren. This summer my wife and I will celebrate our 45<sup>th</sup> anniversary.

I have listed myself as an organ donor since it first became possible to do so on my driver’s license. Today in Maryland about 50% of people getting their driver’s licenses do the same thing.

Mr. Tim Heely  
21652 Joe Hazel Road  
Leonardtown, MD 20650

But that is not enough to provide the organs and tissue to meet the demand. Medical advances have greatly increased the life expectancy of recipients like me – but it is the availability of the organs and tissue that are lagging.

I firmly believe that by educating the public about the life changing difference that they can make by becoming a donor will greatly reduce the wait time for the ailing person.

This bill will go a long way in providing the funds to carry out this education process and will allow so many others the opportunities and second life that I have been given.

Thank you for your consideration.

Sincerely,

*Tim Heely*

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Uploaded by: State of Maryland (MD)

Position: INFO





## DEPARTMENT OF HEALTH

Larry Hogan, Governor · Boyd K. Rutherford, Lt. Governor · Dennis R. Schrader, Secretary

February 23, 2022

The Honorable Guy Guzzone  
Chair, Senate Budget and Taxation Committee  
3 West Miller Senate Office Building  
Annapolis, Maryland 21401- 1991

**RE: SB 574 – Organ and Tissue Donation Awareness Fund - Annual Funding and Extension – Letter of Information**

Dear Chair Guzzone and Committee Members:

The Maryland Department of Health (MDH) respectfully submits this letter of information on Senate Bill (SB) 574 – Organ and Tissue Donation Awareness Fund - Annual Funding and Extension.

The Organ and Tissue Donation Awareness Fund (the Fund) is used to promote public education and awareness about organ, tissue, and eye donations and to maintain a donor registry. SB 574 will alter the annual amount of money distributed from the Fund to a certain qualified nonprofit entity from \$400,000 to \$500,000. If passed, this change will take effect starting in fiscal year (FY) 2024. Additionally, SB 574 will extend the termination date from September 30, 2023 to September 20, 2027.

During the 2018 legislative session, the Maryland General Assembly passed House Bill (HB) 691. HB 691 updated the statute to require at least \$400,000 be distributed annually from the Fund to a certain qualified nonprofit. Prior to the passage of HB 691, the nonprofit would send invoices for reimbursement, rather than receive a set amount of fund distribution.

The Fund consists of optional one dollar (\$1.00) donations collected during the issuance or renewal of state driver's license, as outlined in Transportation Article § 16.111.2(f). Since enactment of HB 691, the Fund has only brought in approximately \$120,000 annually. The Fund is projected to be depleted by FY23; therefore, starting in FY23, the fund will be in a deficit of about \$280,000. The deficit will be \$380,000 if the required distribution is increased to \$500,000.

If you have any questions, please contact Heather Shek, Director of Governmental Affairs, at [heather.shek@maryland.gov](mailto:heather.shek@maryland.gov) or 410-260-3190.

Sincerely,

Dennis R. Schrader  
Secretary