

SAVING SIGHT



VOLUNTEER HANDBOOK

Give Back! Get Involved! Make an Impact!

INFORMATION AND RESOURCE MANUAL

saving-sight.org/volunteer

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Tony Bavuso, CEO

WELCOME LETTER

Dear Saving Sight Volunteer,

Thank you for your willingness to share your time and talents with Saving Sight. Volunteers bring additional scope, depth, knowledge, and personal experience to our work, oftentimes in ways that staff cannot replicate (such as in the case of donor families and cornea recipients). Volunteers like you are a vital part of our mission to change lives by saving sight.

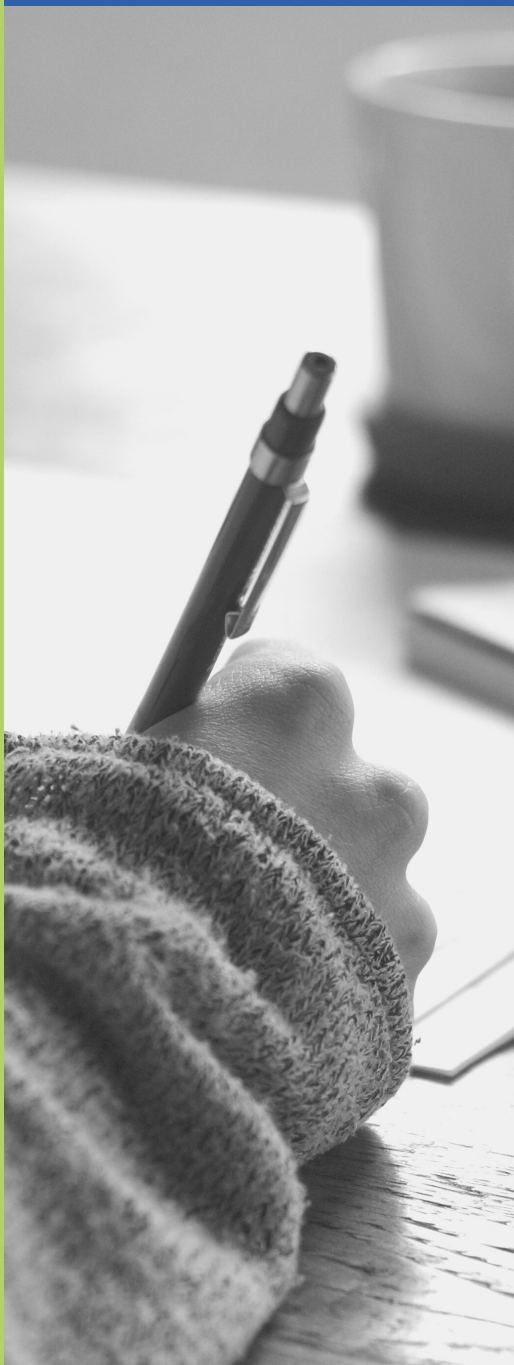
The volunteer handbook includes details about Saving Sight, the roles and responsibilities of our volunteers, tips for speaking about cornea donation, and information about volunteer opportunities throughout the year. If you have any questions please contact our Volunteer Coordinator, Jen Galinski at 573-777-8525.

Again, thank you for your willingness to donate your energy and expertise. We are sincerely grateful and cannot complete our mission without you!

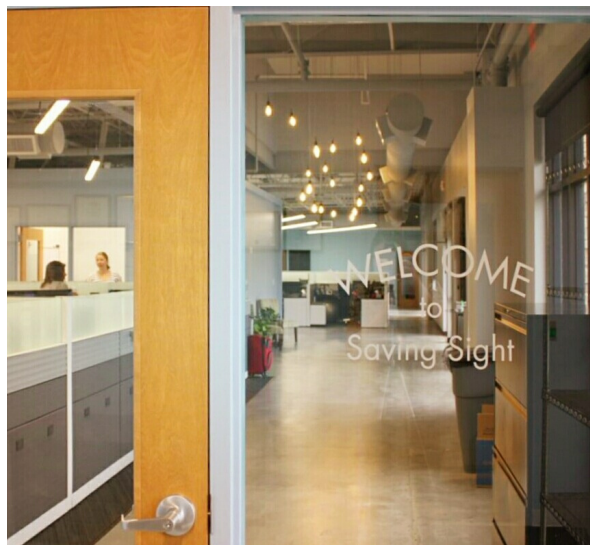
Respectfully,



Tony Bavuso
Chief Executive Officer



WHO WE ARE...



Saving Sight is a 501(c)(3) nonprofit organization with a mission to change lives by saving sight. Founded in 1960, Saving Sight has grown to become one of the nation's leading eye banks and is focused on providing innovative solutions to its clinical partners. Headquartered in Kansas City, Mo., Saving Sight facilitates eye donation in Missouri, Kansas and Illinois, impacting the lives of those both near and far through transplantation.

NEARLY 60 YEARS OF CHANGING LIVES BY SAVING SIGHT

Our vision is to be the global partnership model for how eye banking and charitable vision services can most effectively serve people and communities. Thanks to the support of our organizational partners and the selfless gifts of eye donors and their families, we are able to change lives by saving sight.



MISSION

We change lives by saving sight.®

VISION

To be the global partnership model for how eye banking and charitable vision services can most effectively serve people and communities.

VALUES

Resilience - a quality that enables a person to adapt to change, deal well with the unexpected, and persevere in the face of the unknown.

Innovation - the ability to think creatively and find new solutions to problems or challenges, and to constantly be focused on continuous improvement. This continuous improvement is focused both on the exterior (systems, work processes, and outcomes) as well as the interior (becoming better versions of ourselves).

Initiative - when a person steps up and takes charge to solve a problem, addresses a challenge, or sees when something needs to get done and does it without having to be told.

A person in a superhero costume is jumping over a low wall. In the background, there are several balloons, one of which has a 'DONATE LIFE' logo. The image is overlaid with a green tint and the text 'SAVING SIGHT' written vertically in a large, white, distressed font.

SAVING
SIGHT

Saving Sight

HISTORY

In 1960, the Missouri Lions joined forces with the University of Missouri-Columbia to form the Lions Eye Tissue Bank. The Lions provided financial support, and the University supplied equipment, laboratory space, and staff. This allowed the "Gift of Sight" to become available in Missouri by providing the means to donate eyes, evaluate and distribute the corneas for corneal transplant surgery and utilize non-transplantable parts of donated eyes for research and medical education.

As corneal transplant surgery moved from an experimental technique in a university setting to a fairly common surgical procedure, it was recognized that a larger, "free-standing" facility was needed to serve university and private-practice surgeons alike. The 1970s laid the groundwork for what would eventually become Saving Sight. In 1972, The Eye Research Foundation of Missouri was formalized as a publicly owned, nonprofit organization.

In that same year, the Board of Trustees of the Bethesda Eye Foundation (BEF) in Bethesda, MD agreed to name the Eye Research Foundation of Missouri as its successor and contributed \$850,000 to the newly formed organization. By 1974, the Foundation began construction on its new facility in eastern Columbia, using the BEF resources, \$250,000 contributed by the Missouri Lions, and six acres of land donated by Byron and Gail Keene. The organization moved to its current location and the Missouri Lions continued to support the eye banking activities while the

Foundation added several programs, such as ocular research and glaucoma screening.

At the 1987 State Convention, the Missouri Lions voted to accept financial responsibility for all programs at the Eye Research Foundation, renaming it the Missouri Lions Eye Research Foundation. The Foundation continued to grow throughout the years. St. Louis Children's Hospital and St. Louis-area Lions piloted an amblyopia screening program in 1995 that the Foundation then grew statewide. Today, that program is called KidSight, which operates as an independent 501(c)3 nonprofit.

In 1997, cornea donation operations expanded into central Illinois and Kansas. This prompted the creation of Heartland Lions Eye Banks, with the cooperation of the Illinois and Kansas Lions, which soon became one of the largest providers in the world of human corneas for transplantation and eye tissue for medical research. To date, Saving Sight has provided tissue for more than 40,000 cornea transplant surgeries.

In 2013, the Board of Directors passed a motion to change the name of the organization to Saving Sight. The organization has undergone many transformations over nearly 60 years, and under the strategic plan it will undergo many more, but the mission remains the same: we change lives by saving sight.



WHAT IS AN EYE BANK?

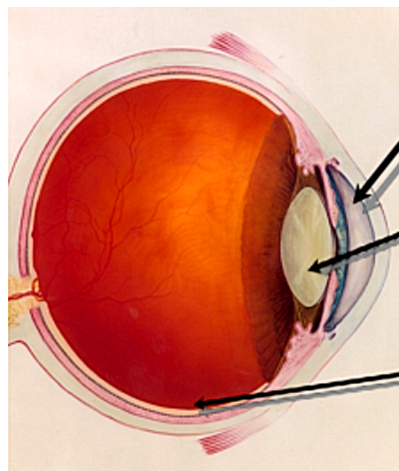
An eye bank is a non-profit organization that obtains, medically evaluates and distributes eyes donated by caring individuals for use in corneal transplantation, research, and education. U.S. eye banks provide tissue for an average of over 70,000 corneal transplants a year.



THE JOURNEY OF THE CORNEA

The Human Eye

The cornea is the clear outer window of the eye that covers the iris and pupil, allowing light into the eye. It is the part of the eye most commonly transplanted. In addition, the sclera (or white of the eye) can be donated and used in other surgeries as well, such as the rebuilding of an eardrum to restore hearing.



Cornea: the most commonly used tissue for transplant; clear outer window of the eye.

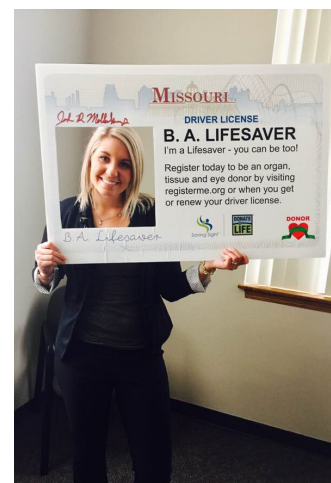
Lens: helps bring rays of light to focus; often used by researchers

Sclera: white outer protective eye tissue; can be used in reconstructive surgery

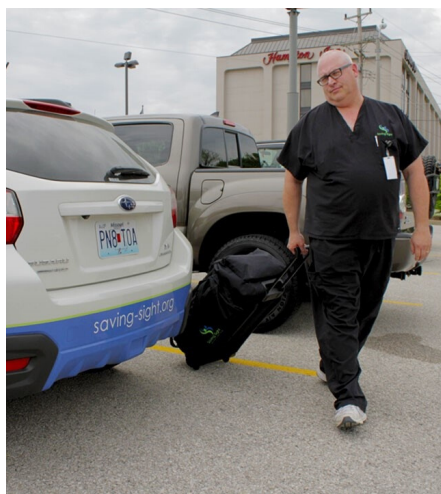
Referral and Initial Screening for Eye Donation

When a death occurs, the hospital or related medical facility places a call to one of three organ procurement organizations in Saving Sight's tri-state area (Missouri, Kansas, and Illinois). The OPO, in turn, relays information to our Donor Services Center (DSC). After gathering initial information, the organizations work together to determine if the person had registered as an eye, organ, and tissue donor.

When consent for donation has been given, the DSC consults medical records and conducts a medical and social history interview with a member of the donor's family.



Eye Tissue Recovery

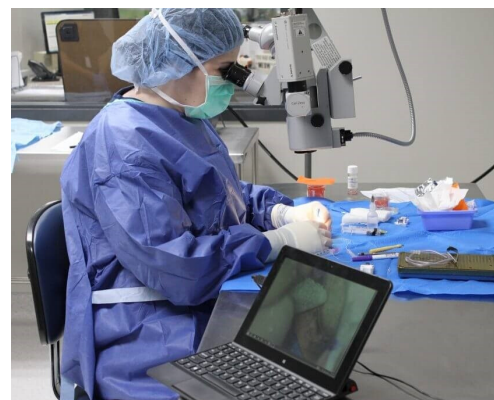


Since eye tissue must be recovered within a few hours of a patient's death, Saving Sight has technicians on-call 24 hours a day, seven days a week. When Saving Sight determines that the tissue is likely to be suitable for transplantation, the technician performs an *in situ* procedure to gently remove the cornea. The cornea is immediately placed in preservation media so it can be safely transported and stored until transplant.

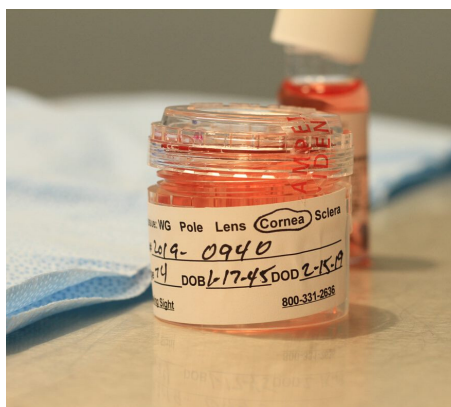
A blood sample is also taken from the donor during the tissue retrieval. The sample is then sent out for testing to detect the presence of infectious diseases like HIV or Hepatitis B or C. All blood samples are tested prior to distribution to eliminate the threat of infectious disease.

Corneal Tissue Evaluation and Processing

At Saving Sight's Kansas City laboratory, the donated corneal tissue is further evaluated for possible transplantation. A high cell count within the cornea is desirable and indicative of healthier tissue. Our lab staff also further processes the tissue for the type of corneal transplant that it will be used for. In some cases, the cornea will be used for a traditional transplant where the donor cornea replaces the full thickness of the recipient's cornea. In other cases, a transplant technique is used where only a thick layer of cells is transplanted.



Corneal Distribution



After a cornea has been cleared for transplant, Saving Sight's Client Services Team meets a corneal surgeon's needs by offering tissue for transplant. All corneal tissue is first offered to surgeons in our three-state region before being distributed nationally and then internationally. Although corneas can be stored for up to two weeks, U.S. physicians usually prefer to transplant donor tissue within five days of retrieval.

We also provide corneas and eye tissue to research teams and educational and training facilities.

Cornea Donation

DID YOU KNOW?

- A cornea transplant may be required because of an eye disease, such as Fuchs' dystrophy or keratoconus, or a corneal injury. Presently, more than 80,000 individuals worldwide receive corneal transplants each year from eye banks accredited by the Eye Bank Association of America.
- Over 95 percent of corneal transplants are successful.
- Saving Sight retrieves and processes corneal tissue for transplantation. Currently, we are able to provide tissue for approximately 7 transplant surgeries per day.
- Almost anyone can be an eye donor, regardless of poor vision, diabetes, or cancer.
- Saving Sight recommends that everyone discuss his or her wish to donate with family and friends.
- For people living in states with first-person consent registries, simply registering at the DMV or through the state's online database will protect their intent. You can also sign up in the National Donate Life Registry at registerme.org. In states without first-person consent, legal next-of-kin of the potential donor must give consent before donor tissue can be retrieved, even if a donor card was signed by the deceased. An exception to this requirement would be made if the deceased had an advanced directive with the power of attorney specifying eye, organ, and tissue donation decisions.
- The cornea is the most commonly used part of the eye in transplant surgery. The sclera, or white protective part of the eye, can also be preserved and used to repair another patient's sclera, eardrum, nasal septum, or gums.
- The cornea gets its oxygen from the air as opposed to the bloodstream.
- The Center for Medicare and Medicaid Services (CMS), under the Department of Health and Human Services, passed a federal regulation in 1998 requiring hospitals to notify organ banks each time a death occurs in the hospital.
- Most major religions support eye, organ, and tissue donation.

Eye Banking and Donation

FREQUENTLY ASKED QUESTIONS

1. Why would someone need a cornea transplant?

There are a variety of reasons why someone might be suffering from vision loss and require a corneal transplant. These can include eye diseases such as Fuchs' dystrophy, in which the endothelial cells of the cornea die off, or keratoconus, which causes the cornea to distort. Other reasons can include corneal injuries or infections.

2. What does a corneal transplant surgery entail?

The type of transplant depends on the eye disease or injury and the preference of the surgeon. In some instances, such as repairing a corneal injury, the entire cornea may need to be transplanted. Another cornea transplant option is a partial thickness corneal transplant surgery like DMEK or DSAEK in which the corneal surgeon replaces only the inner-most layer of the cornea. In many cases, this type of transplant offers less pain and a shorter recovery time in comparison to traditional corneal transplant surgeries.

3. What is the success rate for cornea transplants?

Unlike many organ transplant surgeries, a cornea transplant has about a 95 percent success rate. Matching blood types between donor and recipient is not necessary in most cases. This is due to the fact that the human cornea is avascular, meaning that it does not have blood vessels. Therefore, the body is much less likely to reject a cornea than it would a vascular organ like a heart or liver.

4. How do I become an eye donor?

The simplest way to register to become an eye, organ and tissue donor is to put your name on the National Donate Life Registry at registerme.org. You can register at your local Department of Motor Vehicles office as well. Although your decision to donate is legally binding, we encourage you to notify your family or next-of-kin about your wish to donate so there is no confusion upon your passing.

5. What is your criteria for eye donors?

Almost anyone can be an eye donor, regardless of poor vision or a history of illness, such as cancer or diabetes. Some conditions can prevent eye donation, including HIV or AIDS, Active Hepatitis, Active Syphilis, Rabies, Viral Encephalitis, Leukemia, Active Lymphoma, or Active Meningitis.

If donated eye tissue cannot be used for transplant, it can be offered to ocular researchers across the U.S. who are working to discover the causes of and cures for eye disease.

Continued...

FREQUENTLY ASKED QUESTIONS

6. If I register as a tissue donor, is it true my doctors won't work as hard to save my life?

No. Your doctors are dedicated to saving your life. According to a statement from David Fleming, president and CEO of Donate Life America, "For health professionals, the number one priority is always to save the lives of their patients, and only after death is organ and tissue donation considered."

7. Is eye donation an accepted practice by my religion?

Eye, organ, and tissue donation is accepted by most mainstream religious groups as a charitable act that can save or enhance another's life. Learn more about religion and donation/transplantation at our Religious Viewpoints page (saving-sight.org/religious-viewpoints/). We also have information there about the National Donor Sabbath.

8. Can donor families and tissue recipients correspond with each other?

We understand that for many donor families and cornea recipients, corresponding about their experiences is a key part to the healing process. Saving Sight serves as an intermediary, accepting correspondence from transplant recipients and donor families and then forwarding these letters to the appropriate parties. This keeps the exchange anonymous because the identities of donor families and recipients are kept strictly confidential. For more information about this process, please visit our page on Donor Family and Cornea Recipient Correspondence.

9. How are the Lions Clubs affiliated with Saving Sight?

Saving Sight is the state sight project of the Missouri Lions, and our relationship with the Lions dates back to our origin in 1960. As a result, the majority of our Board of Directors is comprised of Missouri Lions. Lions clubs in Missouri, Kansas and Illinois also provide some financial support to Saving Sight's charitable programs.

10. How can I make a financial donation to Saving Sight?

Saving Sight is able to change lives thanks to donations from generous contributors. To make a financial gift to Saving Sight and invest in the vision of others for years to come, please visit our Give page at saving-sight.org/give.

If there's something you wanted to know but can't find here, please send us a message through our website contact form or give us a call at 800-753-2265.

OPPORTUNITIES AND VOLUNTEER DESCRIPTIONS

VOLUNTEER REQUISITES

- A passion for the cause of eye, organ, and tissue donation.
- First-hand experience as a donor family, recipient, or healthcare professional
- Desire to give back and make an impact.

Saving Sight staff will happily train and coach you through the rest!

PUBLIC SPEAKING

Share your story at one of the many Donate Life, Donor Family, or Hospital Education events Saving Sight participates in throughout the year. Saving Sight staff are available for coaching and to help prepare you for your speaking engagement. Many times, these are short 10-15 minute presentations.

EVENT SUPPORT

If public speaking is out of your wheelhouse, Saving Sight can always use extra hands at the many events we attend and support throughout the year, including Donor Council Meetings, Candlelight Ceremonies, and 5K Runs.

STORY SHARING FOR PRINT AND MEDIA

Share your story or participate in an interview with a Saving Sight staff member. We will publish your story on our website and social media.

SOCIAL MEDIA AMBASSADOR

Help Saving Sight further our mission from home or wherever you do your tweeting! Saving Sight tries to maintain an active online presence and we can always use some extra likes and shares! You can also participate in our online community via our Volunteer Program Facebook group to share your ideas and connect with others.

ART SUBMISSIONS

Are you able to continue creating art with your gift of sight? Did your loved one make art prior to their passing? We love art in all forms at Saving Sight and would love to spotlight your submissions and story on the Featured Artist page of our website.

OTHER

There are always additional ways to get involved, including donor drives, fundraising efforts, and administrative support. We are open to new ways to share our mission!

KNOW YOUR VOCABULARY

Language plays an important role in the misconceptions and the fears about organ, eye, and tissue donation. Please consider how a donor family and the general public may perceive insensitive terminology. As of May 2004, the following terminology was approved by the AOPO Donor Family Council. Avoiding terminology that causes concern among donor families and the general public will not only help further their understanding, but will also improve their acceptance of the donation process. We request that you support the following changes in terminology within your service area.

Please use:

- “Recover” organs not “harvest” organs
- “Recovery” of organs not “harvesting” of organs
- “Donation” of organs not “harvesting” of organs
- “Determine brain death” not “declare brain death”
- “Death” not “legal death”
- “Mechanical” support not “life” support
- “Ventilator” support not “life” support
- “Donated organs and tissues” not “body parts”
- “Deceased” donation not “cadaveric” donation or “cadaver” donation
- “Deceased donor” not “cadaver”



STORY SHARING TIPS

Whether you are sending an email, presenting to your faith group, or having a conversation with someone in line at the grocery store, your personal experience can be the most significant influence in someone's decision to become a registered donor. Below are tips to remember when adding your VOICE to the need for organ, eye, and tissue donors and inspiring your family, friends, coworkers, or neighbors to register.

Remember the goal: The primary goal of sharing your connection to donation and transplantation is to inspire those listening to register as organ, eye and tissue donors. As you think about what details to include and the way you share your story, keep in mind that you want to educate and motivate.

Be your natural self: Even though there is a purpose behind sharing your story with others, that doesn't mean it has to be forced or unnatural. Just be yourself when speaking about your experience. Whether you insert humor, use an analogy or shed tears, your listeners know you so go with what feels right.

Keep it simple – less is more! An important thing to keep in mind is that your story is about you or a loved one, not about the medical process of donation and transplantation. Because of its many procedures and medical terms, this subject can be complex. Though sharing every detail may feel natural, it can be overwhelming to others and they may miss the important message of registering as a donor.

For example: Details like the exact number and names of medicines required after transplantation, or the precise dates of important events throughout your journey are extremely important to you, but including all of them may detract from the power of your story.

Stress the positives – tell, don't dwell! Donation and transplantation can be bumpy roads. Whether you are a grateful recipient, hopeful candidate or family member, focus on the positive feelings you and your loved ones have experienced.

That does not mean to ignore anything that could be negative. Be honest about hardships you or your family may have faced—but focusing too much on them can be counter-productive. Remember, the goal is to educate and motivate. Make your audience comfortable and keep their attention through the positive aspects of your story.

Some Do's and Don'ts: Misusing specific terms can turn someone off or inadvertently reinforce myths. See previous page on appropriate language.

Never attempt to pressure someone into registering. Research shows that using guilt has the opposite effect on what you would want – making that person more resistant to the idea of registering. If someone is uncomfortable registering, even after hearing your story, that is okay! You did all you could do to educate them about donation. And who knows? Maybe when they get home, they may still be thinking about your story, and it could be the seed that eventually changes their mind later down the road.

Speaking Outline

DONOR FAMILY/FRIENDS

General Speaking Outline

1. Introduction

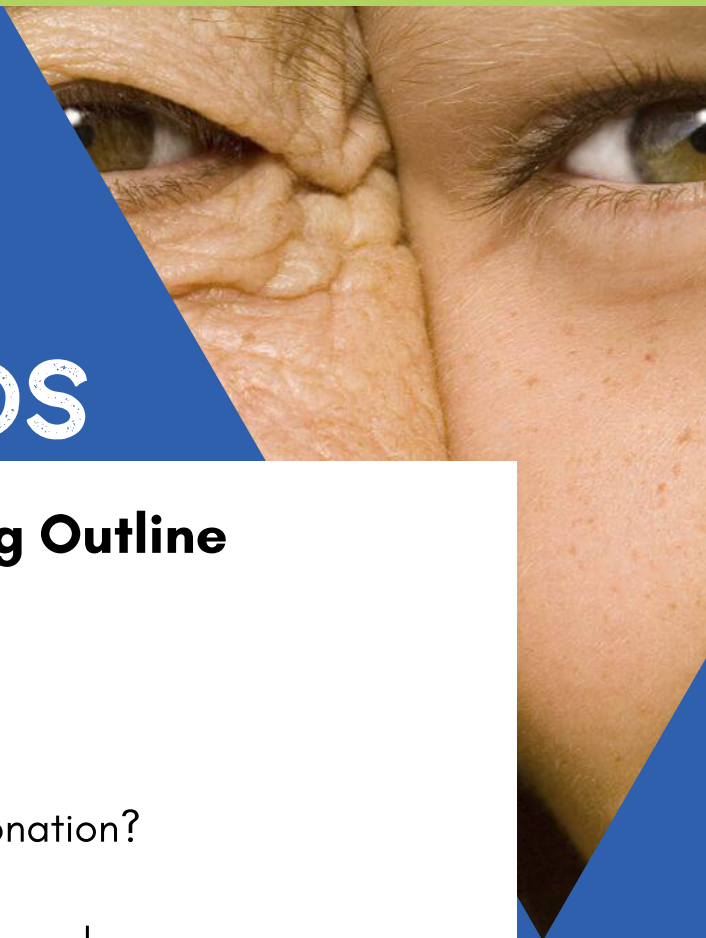
- a. Your name
- b. Who are you?
- c. What is your connection to donation?

2. Tell your story

- a. Tell the audience about your loved one.
- b. Tell briefly about the passing of your loved one if you are comfortable
- c. Describe the decision to donate.
- d. Talk about the impact of donation on yourself, family, and/or friends.
- e. Talk briefly about your feelings for the recipient(s) and any communication that you might have had with them.
- f. Dispel a donation myth or two.

3. Closing

- a. Why is donation important to you?
- b. Discuss the need for donation.
- c. Thank the audience.



Speaking Outline

CORNEA RECIPIENT

General Speaking Outline

1. Introduction

- a. What is your name?
- b. Who are you?
- c. What is your connection to donation?

2. Tell your story

- a. Tell the audience briefly about your life before transplant (Do not use medical jargon unless speaking to medical professionals).
- b. Tell how your illness affected your life and your family.
- c. Talk about your life after your transplant.
 - i. How has your life changed? What can you do now that you were unable to do before your transplant?
 - ii. What future plans have you been able to make with the gift of sight?
- d. Talk briefly about your feelings for your donor
 - i. If you've written to your donor family, please speak to this and what it has meant for you to do so.
- e. Dispel a donation myth or two

3. Closing

- a. Why is donation important to you?
- b. Discuss the need for donation.
- c. Thank the audience.



*Speaking Outline***COMMUNITY MEMBER****General Speaking Outline****1. Introduction**

- a. What is your name?
- b. Who are you?
- c. What is your connection to donation?

2. Tell Your Story

- a. Tell a donation related story that has been impactful to you.
- b. Share your reasons for volunteering with Saving Sight as an advocate for donation.
- c. Dispel a myth or two.

3. Closing

- a. Why is donation important to you?
 - i. Do you know someone who has been touched by donation?
 - ii. Discuss the need for donation.
 - iii. Encourage others to register as a donor.
 - iv. Thank the audience.

DONATION EVENTS AND OBSERVANCES

Rose Parade/Donate Life Float - Annually on New Year's Day, the Donate Life float appears in the Rose Parade to honor millions of people touched by organ, eye and tissue donation.

National Donor Day: February 14th - An observance dedicated to spreading awareness about donation and to recognize those who have given and received the gift of donation, those who are currently waiting, and those who died waiting because an organ was not donated in time.

Eye Donor Awareness Month: March - A time to honor the work of the Eye Bank Association of America (EBAA), corneal surgeons, and the donors and their families who give the gift of sight.

Donate Life Month: April - An entire month of local, regional, and national activities to help encourage Americans to register as organ, eye, and tissue donors and to celebrate those who have saved lives through the gift of donation.

Blue and Green Day - During this observance developed by Donate Life America, the public is encouraged to wear blue and green, hold events and fundraisers, and partner with local organizations to spread awareness about donation and transplantation. For yearly dates and resources, visit donatelife.net.

National Minority Donor Awareness Month: August - National Minority Donor Awareness Month is an annual initiative to save and improve the quality of life of diverse communities by creating a positive and inclusive culture for organ, eye, and tissue donation.

Eye Donation Month: November - Since it was proclaimed by President Ronald Reagan in 1983, EBAA has used the month as an opportunity to educate the public about the importance of registering to be a donor, about cornea donation and transplantation, and to acknowledge the important work of their partner eye banks.

Donor Sabbath: November - On Friday through Sunday, two weekends before Thanksgiving, faith communities across the nation focus on the critical need for organ and tissue donation. Faith leaders and donation professionals lead discussions of issues concerning donation, and faith communities sponsor donation awareness activities, donor registrations and speakers.

ANNUAL VOLUNTEER OPPORTUNITIES

Saving Sight participates in a myriad of events throughout the year. To take part in any of these events or to inquire about additional opportunities, including hospital rounding, please contact Saving Sight's Volunteer Coordinator, Jen Galinski, at 573-777-8525 or jgalinski@savinvg-sight.org

January

- National Rose Parade/Donate Life Float

February

- National Donor Day

March

- National Eye Donor Month
- Springfield, MO Candlelight Memorial Ceremony (SW MO)

April

- National Donate Life Month
- National Blue and Green Day
- Donor Family Recognition Day at the Missouri Capital (Mid MO)
- National Volunteer Week
- Mosaic Life Care Celebration of Life Ceremony (KC MO)
- Joplin, MO Celebration of Life Ceremony (SW MO)

May

- Midwest Transplant Network Legacy Walk (KC MO)

August

- National Minority Donor Awareness Month

September

- Memorial Medical Center 5K Run-Walk for the Transplant Patient Assistance Fund (Central IL)

October

- Mid-America Transplant Celebrate Life 5K Run/Walk (STL Area)

November

- Eye Donation Month
- National Donor Sabbath

December

- Holiday and end of year fundraising

Additional opportunities to attend a donor council or assist in hospital rounding along side of our Hospital Development Managers at many of our area hospitals are available upon request.



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