

VISION

Chicago • Bloomington • A Subsidiary of Midwest Eye-Banks • Spring 2014 & Annual Report



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Visit the Illinois
Eye-Bank website

VISION

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From our Executive Director



This year, I was truly obsessed with the Winter Olympics. I admire the courage and fortitude it takes to become a world-class athlete. I feel the same way about our donor families, recipients and the incredible staff at the Illinois Eye-Bank. They are my Olympians! I am inspired by the selfless act of a donor and a donor family, the perseverance of someone with impaired vision and the dedicated eye bank staff.

This issue of Vision takes a look at Fuchs' Dystrophy, a degenerative disease leading to the loss of vision and the journey Eileen Hoban took to get her sight back. We will also take you behind the scenes of the Illinois Eye-Bank to better understand the incredible gold medal-worthy work that the staff performs each day.

You will also read about the Transplant Games of America, taking place July 11-15 in Houston. The transplant community is holding the Olympic-style games in order to raise awareness about the need for eye, organ and tissue donation. This year, for the first time ever, the Transplant Games include cornea and tissue transplant recipients in addition to organ recipients, living donors and donor families. Join Team Illinois and see this amazing event for yourself.

I hope you will all join us for one of our upcoming events: the third annual Black and White Night for Sight, May 29 at the ISU Alumni Center, or the 16th annual Gift of Sight Gala, A New Chapter, June 19 at the Peninsula Chicago. Both of these events raise funds for those in need of cornea transplants and critical research to find cures for blinding eye conditions.

Enjoy!



Diane Hollingsworth
Executive Director

Have you written to your donor family?

Whether it has been several weeks or several months since your transplant, donor families appreciate hearing from those who have benefitted



from their loved one's gift. We invite you to share your story in a letter or send a card thanking them.

"My family and I were having a hard time dealing with the loss

of my wife, but after receiving the letter from her transplant recipient, we can rest a bit easier knowing she was able to give someone the gift of sight," one donor husband said.

The Illinois Eye-Bank keeps all donor and recipient information confidential, but we are always happy to help you reach out. For more information on writing to your donor family, please contact Nesha Logan at (312) 469-5589.

Illinois Eye-Bank is proud to support ocular research

Cornea transplants preserve sight for thousands of people in need; however, even more suffer from blinding eye conditions or other visual impairments that cannot be treated through transplantation. The Illinois Eye-Bank proudly supports ocular researchers identifying the causes and cures of all blinding eye conditions. We do this by funding research grants and providing donated ocular tissue. Because of the generosity of donors and their families who say yes to donation for transplant and research, the Eye-Bank can continue to support the many groundbreaking ocular research projects in the U.S.

Meet our newest staff member!

The Illinois Eye-Bank is pleased to introduce Brittany Wright, our new community relations liaison. Brittany will be responsible for community



outreach, special event support, fund development and overseeing the Ambassador program.

In her spare time, Brittany enjoys exploring Chicago with her friends, experimenting with

new recipes in the kitchen, visiting her family in Wisconsin and attending football games at her alma mater, Northwestern.

For any community relations needs, please contact Brittany at bwright@illinoiseyebank.org.

National Eye Donor Month

In March, we commemorated the 31st annual National Eye Donor Month. Donation and transplantation communities across the nation took this opportunity to honor eye tissue donors and their families, celebrate the gift of sight



NATIONAL
EYE DONOR
MONTH

with cornea recipients and encourage people to join the donor registry. Last

year, 1,136 Illinoisans received the gift of sight through transplantation thanks to the amazing generosity of our donors and donor families. Thank you for all you do to make sight restoration and preservation possible!

Look for our daily updates on Facebook and Twitter for exciting news about the Eye-Bank!

BEHIND *the* SCENES

Recovery, clinical staffs play essential role in sight restoration



Senior Processing Technician Dalene Youngblood evaluates corneal tissue



Elsa Arteaga

Sight restoration would not be possible for cornea transplant recipients without tissue donors, the support from our donor families, as well as the efforts of our clinical and recovery staffs, which work tirelessly behind the scenes. Chicago Clinical Manager Elsa Arteaga, Bloomington Clinical Manager Bob Albrecht, Recovery Manager Kraig Markland and their staff of 20 carefully recover, evaluate and prepare donor tissue so the Eye-Bank can provide the best possible outcome for those in need.

Information gatherers

Once the Illinois Eye-Bank receives authorization for a donation, Arteaga's or Albrecht's team jumps into action, collecting as much information as they can about the donor. While the recovery team surgically recovers the tissue, clinical staff pulls together a variety of records to create the most thorough medical and social history possible, including hospital charts, files from primary care physicians and documents from medical examiners and coroners. During this process, clinical technicians examine the tissue under two different microscopes for potential red flags like surgery scars, low cell counts or infections which can indicate unhealthy or non-surgical tissue.

After the team has compiled the records and examined the tissue, they pass it along to another clinical staff member, the donor eligibility coordinator, who makes the final decision whether tissue should be used for transplantation. Tissues that cannot be transplanted can be used for research or education with the appropriate authorization.

Compiling these case records takes between 24 and 48 hours. Arteaga said the team's goal is to get the information collected and the tissue ready for surgical use within a day. The Chicago and Bloomington offices work closely together to provide tissue for patients in need.

"Our office works very hard to thoroughly investigate the donor's history to make sure we are making the best use of the donor's amazing gift and ensuring the recipients' safety," Arteaga said. "We are so grateful to our donors and their families, and our staff takes pride in helping to restore vision."

Prepping the tissue

Once a cornea has been cleared for transplantation, information about it is logged into a software program, Midwire. Surgeons can enter requests for tissue into Midwire Match, at which point they are also able to request how they would like the tissue prepared by Arteaga's team of technicians for the best patient outcomes.



Lab Technician Serena Loranca measures corneal thickness

The most common type of preparation for surgery is Descemet stripping automated endothelial keratoplasty (DSAEK) which modifies the cornea to a thickness approximately the width of a human hair or one-sixth the width of the average cornea. Transplants using DSAEK tissue allow some of the recipient's cornea to remain intact, which helps prevent the donor tissue from being rejected. Cornea transplantation has the highest success rate of any type of organ and tissue transplant, as more than 90 percent of surgeries are successful.

On the cutting edge

In the winter of 2012, Midwest Eye-Banks staff began refining a new tissue preparation technique that would benefit patients whose cornea conditions only affect the innermost layer. Descemet's membrane endothelial keratoplasty (DMEK), takes the DSAEK procedure a step further. The result is a cornea graft that is five times thinner than the traditional method. This procedure may provide even greater success rates with some patients.

"Depending on the patient, a DMEK graft might be the best choice," said Lauren Johnson, a processing technician who helped develop the Eye-Bank's DMEK procedure. "The time it takes for visual rehabilitation, the rate of complication and the aftercare needs associated with DMEK are all very low."

The procedure to transplant this type of tissue is very delicate and time-consuming. Surgeons are still perfecting the technique so patients have the best visual outcomes. Demand for DMEK-prepared tissue has been slowly increasing since Midwest Eye-Banks began offering the service in July 2013, and Johnson said she expects it to continue to grow in popularity as more surgeons train with this technique.

For more information, please contact Mary Schlereth, the professional relations liaison at our Chicago office, at mschlereth@illinoiseyebank.org or (312) 469-5571, or David Hearn, the professional relations liaison at our Bloomington office, at dhearn@illinoiseyebank.org or (312) 469-5572.



Causes and treatments of Fuchs' dystrophy

By Dr. David Lubeck



Special thanks to David M. Lubeck, M.D., for providing this educational description of the ocular disease Fuchs' dystrophy. Dr. Lubeck is a distinguished specialist in cataract, corneal and refractive surgeries at the Arbor Centers for Eye Care in the Chicago area.

A loss of vision can be frightening and bewildering, but a visit to an eye care professional is the first step to treating eye conditions and preserving sight.

Someone experiencing this may ask, "Why me?" For some people, decreasing or absent vision may be a result of an uncommon disease known as Fuchs' dystrophy, a syndrome in which the cells lining the inner surface of the cornea gradually expire.

Fuchs' dystrophy is a type of corneal dystrophy. The early clinical signs of the disease include a reduced number of endothelial cells and small lesions in the corneal endothelium, referred to as corneal guttata.

The causes of Fuchs' dystrophy are unknown – the disease can be inherited, or it can occur without a known family history of the condition. Usually, vision problems do not appear before age 50, although ophthalmologists may be able to detect signs of the disease in patients in their early 30s and 40s.

The only way to be diagnosed with Fuchs' dystrophy is to receive a comprehensive eye exam from an ophthalmologist.

Despite potential anxiety and fear associated with a diagnosis of Fuchs' dystrophy, there is great hope in ocular treatments.

In addition to working with an ophthalmologist, it is as essential to practice self-education.

Don't hesitate to ask your eye care professional questions about the disease or for additional information from reputable resources.

Many patients living with Fuchs' dystrophy can have their sight preserved and/or restored through specialized therapies as a result of ocular research and medical advancements.

Finding the best therapy option often depends on the severity of the disease. For patients whose symptoms have dramatically progressed, corneal transplantation is often the only probable treatment to ensure sight preservation and/or restoration.

For patients who receive corneal tissue, it is important to inform them of its origin. Stating that a generous donor and donor family made the decision to give the gift of sight is a powerful message.

As always, if you experience any unusual ocular symptoms or concerns related to your eye health, it is important to notify your eye care professional. Symptoms requiring medical attention may include:

- Eye sensitivity to light
- Eye pain
- Worsening of vision
- Obstructed vision

Eating well and practicing proper eye health habits, including proper contact lens care, are great potential preventative measures to eye disease!

'Every time I read, I think of my donor'

Eileen Hoban always found happiness with her nose in a book, but that joy was threatened when her vision began deteriorating.

Hoban, 75, had noticed problems with her vision for years but struggled to find a solution. She was going through three pairs of glasses every year, constantly cleaning them in an effort to clear the cloudiness in her vision, but the doctors she visited could not find the cause.

Finally, ophthalmologist David Lubeck, M.D., diagnosed her with Fuchs' dystrophy, a disease in which the cells in the endothelium (the innermost layer of the cornea) gradually expire. As the cells die, fluid builds up in the cornea, causing swelling and cloudy vision. (For more information, see article on the left.)

"Before he examined my eyes, I had gone to multiple specialists and no one ever found [the cause] before him," Hoban said. "Everything was beginning to go blurry. I never thought this would be possible, that my sight could be saved."

Hoban received two cornea transplants in 2013, four months apart. Though she was uncertain about the procedure when Lubeck first suggested it – she had never heard of corneal transplantation before – she was willing to try anything if it meant she could read again.

"I didn't know just how it was going to turn out, but I figured I was not going to waste any time asking questions," she said. "I was flabbergasted when they told me, 'You mean I'll be able to see? I'll be able to read?' And he said, 'Yes, we'll get you reading.' I was like a child on Christmas morning. I've never been so happy in my life, never. I couldn't believe it was me that this was going to happen to."



From left: Dave Hearn, IEB Central Illinois Relations; recipient Eileen Hoban; Dr. David Lubeck and Brittany Wright, IEB Community Relations.

After she received the first transplant, in her left eye, Hoban was able to read again right away. She is an avid promoter of the donor registry to the people in her life, and her husband, children and daughters-in-law have all become registered donors since her transplants. Hoban also wrote a letter to her donor's family after receiving her transplant to thank them for their gift.

"It breaks my heart, but I am so thankful that they had such a wonderful son or daughter or sister or brother that did this, that gave this gift," she said.

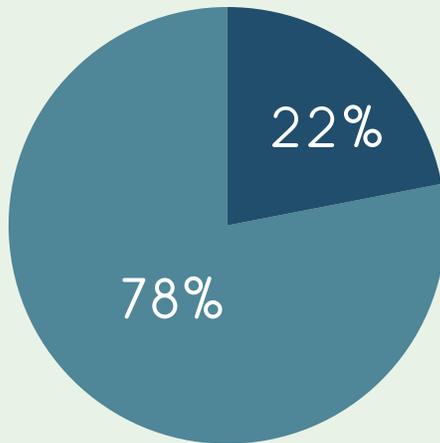
"I absolutely love them... I don't think I could say everything I want to the donor family, to express how much I appreciate it."

Hoban is back to being a bookworm, and purchased an e-reader to celebrate her restored sight. She described her new vision as "absolute Heaven."

"I thank God every single day I wake up that I can see," she said. "...Losing eyesight is the worst thing that can happen to you. I'm just so appreciative. I don't know why I was so lucky, but I am forever, forever grateful."

FY 2013 ANNUAL REPORT

REVENUE

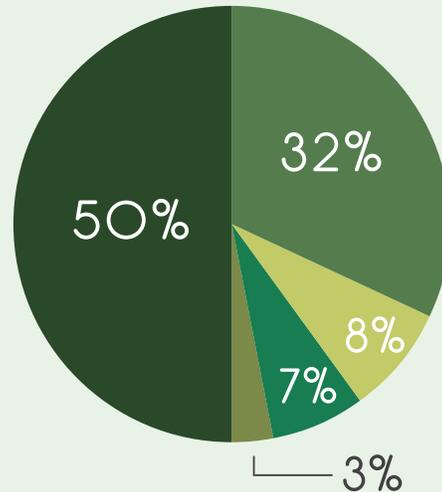


- Public Funding, \$262,397
 - General, \$205,964
 - Restricted to charitable care, \$37,733
 - Grants, \$18,700
- Clinical Processing Reimbursements, \$911,951

TOTAL PUBLIC SUPPORT & REVENUE
\$1,174,348

BEGINNING OF YEAR NET ASSETS
\$342,226

EXPENSES



- Community & Professional Relations Program, \$565,044
- Intercompany expenses, \$355,380
- Fundraising, \$88,244
- Administration, \$78,312
- Gift of Sight Charitable Tissue Program, \$36,696

TOTAL EXPENSES
\$1,123,675

END OF YEAR NET ASSETS
\$392,889

IN COLLABORATION WITH MIDWEST EYE-BANKS

CHARITY CARE, \$494,100
RESEARCH GRANTS \$281,192

Please note: To protect the privacy of those who have generously decided to support the Illinois Eye-Bank, we no longer print the names of our contributors in the annual report.

2013 COMMUNITY ACHIEVEMENTS

2,871



INDIVIDUALS received a second chance for sight restoration through corneal transplantation with tissue from the Illinois Eye-Bank.

1,320

of these cornea transplant recipients are Illinois residents.

220,924



PEOPLE BECAME MEMBERS of the Illinois Organ/Tissue Donor Registry in 2013, joining the more than 5 million donors already registered.



GENEROUS DONORS helped give the gift of sight to others by donating cornea tissue.



EDUCATIONAL/AWARENESS PROGRAMS reached over 7,000 people. The programs were a combined effort of IEB Community Engagement and Professional Relations staff and designed to educate both community members and professional partners.

\$494,100



IN FUNDS PROVIDED in conjunction with Midwest Eye-Banks to those who could not otherwise afford the costs of corneal transplantation. They were given the gift of sight thanks to the funds raised through our charitable support program, which enables us to waive our normal service fees for the provision of eye tissue.



NEXT OF KIN AND RECIPIENT FAMILIES connected this year as a result of our correspondence program.



EYE AND VISION RESEARCH PROGRAM GRANTS, totaling \$258,860, were awarded in conjunction with Midwest Eye-Banks to help support research involving diseases of the retina.



CORNEAL TISSUES were provided for research and education to help preserve and restore sight.

1,459



Photo credit: Spectrum Health Michigan

Transplant Games of America welcomes cornea recipients

The Transplant Games of America are always an exciting opportunity to celebrate the lives of organ and tissue donors and recipients, but this year is especially exciting. For the first time ever, cornea transplant recipients have been invited to participate in the Games and will be represented on Team Illinois.

The Transplant Games of America is a multi-sport festival event for recipients of lifesaving transplant surgeries. The competition is open to organ recipients, living donors, bone marrow recipients and now cornea recipients. The Games bring together 2,500 individuals for a four-day event that highlights the necessity of eye, organ and tissue donation and celebrates the lives of donors and recipients on a national stage.

We are proud to have two Eye-Bank Ambassadors serving as the donor family liaisons for Team Illinois: Sheila and Terry Walters, whose son Caleb donated his corneas after he died in a motorcycle accident.



The Walters were devastated at the news that their son would not be able to be an organ donor, but their spirits were lifted when they were contacted by the Illinois Eye-Bank and informed that their son's corneas could be donated.

"We wanted so much to fulfill our son's final wish," Terry said.

In the years following Caleb's passing, they have found peace and comfort in the knowledge that his final gift restored sight to two people and changed their lives forever.

"It was like receiving a part of Caleb back," Sheila said.

"Caleb does live on in our hearts, but now he will also live on in two people and touch their lives in unique and special ways."

Since their personal experience with donation, the Walters have formed a personal bond with one of the women who received Caleb's gift of sight, and have become active Ambassadors for the Illinois Eye-Bank. As Team Illinois' donor family liaisons, Sheila and Terry will play an essential role supporting their team's donor families by communicating with each family, inviting them to participate in the Games and attending all family-related events.

The 2014 Transplant Games will be held July 11-15 and feature 15 diverse athletic events, including badminton, cycling, darts and ballroom dancing. Each sport allows the competitors to display their talents while honoring the impact of their life-changing gifts. In addition to the sporting events, the days and nights are filled with an array of non-competitive activities so everyone can join in the fun. More than 40 teams from across the country will gather in Houston for the event.

"Our path with the Illinois Eye-Bank would not have been one chosen without the loss of our son, but it has provided rewards and blessings never dreamed of," Terry said. "We have been able to attend the national Transplant Games and feel the love and bond as recipients have adopted my wife and I as their donor family. We have experienced the hugs of compassion as donor families share their loved one's story. Our lives have been changed and we are better for it."

For more information on the Transplant Games and Team Illinois, please contact Nesha Logan at nlogan@illinoiseyebank.org or (312) 469-5589.

how you can support OUR MISSION

Since the Illinois Eye-Bank was established in 1947, more than 80,000 people have benefited from our services. The Illinois Eye-Bank provides tissues for transplantation, research and educational purposes each year to achieve our mission of preserving and restoring sight. We achieve this mission through a variety of programs, which are funded in part by generous charitable donations.

HOW YOU CAN HELP

Helping restore someone's vision is simple. By making a financial contribution to the Illinois Eye-Bank, you can give someone an opportunity to live a life filled with sight.

Your contributions support our mission in a variety of ways and can be given online at www.illinoiseyebank.org, or via mail or phone. Before giving to the Illinois Eye-Bank, check with your employer. Many companies offer programs that will match your charitable contribution, which can double or even triple the impact of your life-changing gift! You can also make your contribution in honor or memory of a loved one.

If you would like to leave a lasting legacy in support of our mission, you can take part in our planned giving program, which allows individuals to name the Illinois Eye-Bank as a beneficiary in their financial or estate plans.

The Illinois Eye-Bank is a 501(c)(3) not-for-profit organization. Our Federal Tax ID is 27-3107617.

If you would like to discuss how you can best support the mission of the Illinois Eye-Bank, please contact Executive Director Diane Hollingsworth at (312) 706-6765 or dhollingsworth@illinoiseyebank.org.



OUR PROGRAMS



THE GIFT OF SIGHT

In Illinois and across the country, people living with blinding eye conditions sometimes face challenges in receiving the care they need because they lack adequate health insurance. In an effort to help these individuals, the Illinois Eye-Bank created the Gift of Sight program to reduce or eliminate the costs associated with sight-restoring cornea transplant procedures. The Illinois Eye-Bank has never denied services to anyone in need of a cornea transplant due to inadequate health insurance.

THE GIFT OF HOPE

The Illinois Eye-Bank has helped restore sight to thousands of people through corneal transplantation, but there are many individuals whose vision problems cannot be cured through transplants. Vision research initiatives, supported by the Illinois Eye-Bank through grant funding and the provision of donor eye tissue, bring new ideas to light for the treatment and prevention of blinding eye diseases.

THE GIFT OF KNOWLEDGE

Our commitment to the restoration of sight also extends to public and professional education programs. The Illinois Eye-Bank's Gift of Knowledge program strives to educate the community about the ongoing need for eye, organ and tissue donors, and the importance of joining the Illinois Organ/Tissue Donor Registry. In addition, our professional relations staff works closely with hospitals, hospices, funeral homes, medical examiners, coroners, corneal surgeons, and surgical facilities to ensure that the donation and transplantation process is effective in serving those in need.



DEDICATED TO THE RESTORATION OF SIGHT
A SUBSIDIARY OF MIDWEST EYE-BANKS

547 West Jackson Blvd., Suite 600
Chicago, IL 60661



Mark your calendars!



Black and White Night for Sight

Thursday, May 29, 2014, 6 - 9:30 p.m, Illinois State University
Alumni Center

Join us as we take you to the city of lights with a Parisian-themed evening with delicious cuisine, cocktails, music and a live auction.

This event will honor Dr. Robert M. Lee for his 20 years of dedicated service to the preservation and restoration of sight. Karen Magers, a member of the Illinois Eye-Bank Board of Directors, is serving as event chair.

Proceeds will benefit the Dr. John E. Randolph Memorial Fund for Illinois residents who could not otherwise afford the costs of a cornea transplant.

16th Annual Gift of Sight Gala

"A New Chapter," Thursday, June 19, 2014, 6 - 10 p.m.
The Peninsula Chicago

Join us as we honor Charles Bouchard, M.D., Gift of Sight Honoree and author Sherrill Bodine, Woman of Vision for cocktails, dinner, dancing and inspiration. Event Co-Chairs are David Donnersberger, M.D. and Eileen Howard-Weinberg. Proceeds will benefit critical research into the cure for blinding eye conditions.

For more information on either event, visit www.illinoiseyebank.org or call (312)-706-6751.