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Increasing the Availability and Quality of Donor Eyes for Research

Andrew M. Williams, BA¹, W. Daniel Stamer, PhD², and R. Rand Allingham, MD²

¹Michigan State University College of Human Medicine, Grand Rapids, MI

²Duke University Eye Center, Durham, NC

Availability of human eye tissues has fueled major advances in understanding the mechanisms of blinding diseases through laboratory research. This is particularly true for eye diseases that occur primarily in humans, such as age-related macular degeneration and open-angle glaucoma. As a recent example, experimentation on human eye tissue laid the foundation for recent development of Rho-kinase inhibitors, a novel class of glaucoma therapeutics that increase aqueous humor outflow facility.¹ Unfortunately, during a time of some of the greatest discoveries in vision science, researchers face a shortage of human eye tissue, as the number of eyes donated for research continues to decline.²

Fortunately, there is great potential both to ameliorate the shortage of donor eyes and to increase the quality of human tissues available for scientific inquiry. Recent surveys have examined attitudes of patients and their families regarding eye donation for research, and this work has found that many patients are interested in donating their eyes for research but are unaware of the opportunity to do so.³ In fact, 90% of surveyed patients indicated that they would consider donating their eyes, but only 10% reported being registered eye donors.³ The reasons potential donors were not registered included never being asked (37%) or feeling that their eyes were either too unhealthy (24%) or too old (4%) to donate. Notably, only 15% of patients stated they would not donate their eyes because of prohibitive reasons, such as religious objection or a desire to maintain body integrity after death. Furthermore, family members of potential eye donors almost unanimously stated that would support their loved one's wish to donate (96%).³

We propose three complementary solutions that could help to close the gap that exists between scientists in need of tissue and patients with an interest in donating their eyes for research.

First, eye care professionals could inform their patients about the opportunity to donate their eyes for research. Currently, the decision to donate eyes or organs is often made near the time of death, when emotional exhaustion is a frequent reason for refusal by the terminally ill patient or their family members. Although family members overwhelmingly support their relative's decision to donate eyes after death,³ only about half of organ donors have

Corresponding Author: R. Rand Allingham, MD, Duke University Medical Center, Box 3802, Durham, NC 27710, rand.allingham@duke.edu, Office: (919) 684-2975, Fax: (919) 681-8267.

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discussed their decision to donate with their family.⁴ In light of these obstacles, the physician's office could be an underutilized setting in which to initiate this conversation.⁵ Patients report preferring to learn about eye donation from their ophthalmologist or from pamphlets in their doctor's office,³ and the majority of patients and their family members find it appropriate for their physician to ask about eye donation.⁵ Therefore, physicians or trained staff members could inform patients about the opportunity to donate their eyes—for research or for corneal transplantation—in the clinical setting to enable interested donors to inform their families and to establish an advance directive to ensure fulfillment of their selfless wish to donate.

Second, innovative collaboration between research institutions and eye banks could maximize the contribution of tissue from expired donors. As an example, the Duke University Eye Center and North Carolina's Miracles in Sight Eye Bank recently implemented a number of operational changes to improve the number and quality of eyes from research donors.⁶ This Duke-Miracles in Sight Program delivers procured tissue directly to researchers, widens age restrictions for research donors, and grants scientists access to donors' electronic medical records. This program has halved the interval between the time of death and access by researchers through delivering donor tissue directly from the Duke University Hospital to adjoining eye center research labs, rather than first routing it through the eye bank headquarters. Importantly, this reduced post-mortem interval results in higher quality tissue—especially a greater number of eye pairs received within six hours of death—which is critical for current techniques to study DNA, RNA, and related molecules involved in the cellular processes of health and disease.⁷ Additionally, this program has increased the total number of eyes for research by instituting protocols to ensure that donors and their families could elect to donate eye tissue for research if the donor is ineligible for tissue transplantation. Finally, this program seeks to ensure adequate clinical documentation of donor tissue by allowing the eye bank and the receiving researcher access to the donor's medical records—a benefit made possible by integration of the electronic medical record across the university medical center. The Duke-Miracles in Sight Program has improved the number, quality, and documentation of donor eye tissue for research, and aspects of this program can be adopted by other centers.⁶ With a critical mass of eye researchers, this program reduced costs for the eye bank to procure tissue for the advancement of research, a core part of its mission. Such collaborations between research institutions and eye banks can greatly reduce the shortage of eye tissue for science while simultaneously maximizing the value of each donor's invaluable gift.

Third, an eye donation registry for research could better facilitate processing of donated eye tissue. For example, Eversight Eye Banks is developing a disease-specific registry for eye donors, which would allow donors to associate their tissue and medical records to an ocular biobank for use by scientists who conduct research on their disease.⁸ On a larger scale, a national eye donation registry for research has been proposed.^{3,5} This pledge-based registry would function as an addendum to the existing Donate Life registry of enrolled eye, tissue, and organ donors that would allow donors to communicate their wish to donate for research after death. In this registry, donors could also grant researchers access to their medical records at the time of death to ensure optimal documentation for research scientists. By building upon existing infrastructure, including the ability for donors to register online, an

eye donation registry for research would provide an efficient approach to link donors and eye researchers. Ophthalmic patients, their family members, and eye care professionals have indicated support for such a registry,^{3,5} and similar models are already in place for other research tissues, including the Veterans Affairs Biorepository Brain Bank and a national registry for temporal bone donations to ENT surgeons.⁵

In conclusion, there is a clear need to improve access to well-documented, fresh human eye tissue to advance the vision science that depends on it. Physician- or staff-initiated discussion can help to increase patient awareness about the opportunity to donate, helping to meet these needs. Additionally, instituting operational changes can help increase procurement rates for registered donors, reduce death-to-preservation time, and incorporate key clinical information with tissues. Collaborative programs between research institutions and eye banks have demonstrated feasibility of this approach.⁶ On a larger scale, a pledge-based eye donation registry for research would enable donors to communicate their specific wishes as a donor to the clinical and eye research community. Sustainability of these programs will depend in part upon adequate reimbursement to eye banks and investigators' incorporation of tissue costs in funding applications. Lastly, increased availability of fresh tissue will undoubtedly improve the quality of data derived from these tissues in published research studies. Ophthalmologists, vision scientists, and eye banks should continue to investigate innovative methods for maximizing the impact of a patient's invaluable anatomic donation to science.

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