

NDRI Research Brief

News from National Disease Research Interchange

September 2006

Welcome to the latest edition of NDRI Research Brief. In this issue you'll learn about the growing need for eye tissue from young donors and donors with diseases like glaucoma, macular degeneration and diabetic retinopathy. Also, read about opportunities to support research into rare diseases. Don't forget to enter the "Mystery Microscopy" contest for a chance to win a \$25 gift certificate to Amazon.com.

Please don't hesitate to call me at 800-222-NDRI if have any questions about providing tissues or organs for research.

Jeff Thomas, NDRI Director of Donor Services

Changes to UAGA May Benefit Research

Recent changes to the Uniform Anatomical Gift Act (UAGA) should help facilitate more donations for research by clearing up ambiguous language that has impeded some research donations in the past, according to Christina W. Strong a New Jersey-based attorney, who worked with NDRI representatives on effecting these changes.

The amendments to the law were approved by the National Conference of Commissioners on Uniform States Laws in July, but do not become legally binding unless and until they are adopted into law by the individual states. Strong expects most states to adopt the revisions within the next few years, given the need for the changes and the widespread support of the stakeholders who participated in the drafting process. "There's huge consensus about the new changes because they clarify the law and we're committed to getting them enacted," said Strong.

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FEATURED RESEARCH

Seeing through the Causes of Age-related Blindness

Imagine the faces of loved ones obliterated by dark splotches or tinted in brown, or one's view of the world akin to what is seen through a tunnel, except the tunnel's opening gets smaller over time. This is what more than three million Americans confront each day as they live with eye diseases that have hampered their vision and threaten to cause blindness, according to the National Eye Institute (NEI).

Many of the eye diseases that are the most common causes of blindness are neither fully treatable nor preventable yet. This raises the need for research to fully understand these diseases and develop better ways to avoid or relieve them before they strike the currently graying American

population. Low vision and blindness increase significantly with age, particularly in people over age 65.

Genetic studies and research on animals have turned up some promising leads for the causes of blinding eye diseases and ways to better treat or prevent them. These studies have uncovered molecular culprits for age-related macular degeneration and diabetic retinopathy, both of

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Jean-Luc Kokel / Photo Researchers, Inc



A fundus image showing long-standing diabetic retinopathy.

► *Seeing through the Causes of Age-related Blindness continued*

Images show normal vision and vision as it might appear if impaired by age-related diseases of the eye.



Normal



Glaucoma



Diabetic Retinopathy



Macular Degeneration

Photos courtesy of National Eye Institute, National Institutes of Health

which damage central vision. Researchers have also discovered possible molecular or cellular triggers for glaucoma, which destroys peripheral vision, and cataracts, which cloud or tint vision. In order for research on blinding diseases to progress, researchers need healthy and diseased eye tissues to compare and understand the workings of these suspect molecules or cells.

There is a growing need for eye tissue from young donors.

“Animal models of human eye diseases are only a partial substitute for the real thing,” said Dr. Paul Sieving, Director of the National Eye Institute. “The human eye has specialized structures that mice, cats and dogs don’t have, and a lot of human vision diseases affect these structures. If you want to study these eye diseases in humans you need human tissue,” he stressed.

There is a growing need for eye tissue from young donors especially the tissue in the back of the eye (posterior pole) where such diseases as glaucoma, diabetic retinopathy and macular degeneration inflict their greatest damage. Researchers are particularly interested in studying whole eyes or eye tissue removed from people with age-related eye diseases.

“We’re not looking for pristine, perfect eyes. In fact, the eyes that have aging eye disease are the most valuable,” said Dr.

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Looking into Eye Disease

• MACULAR DEGENERATION

There is mounting evidence that age-related macular degeneration is caused by an immune response gone awry, possibly triggered by a herpes virus called cytomegalovirus. To confirm this, researchers are exploring whether this virus lurks in the retinas.

• GLAUCOMA

With glaucoma, fluid that continually flows in the eye is often blocked from draining normally through spongy tissue called the trabecular meshwork, which underlies the cornea. This blocked flow may stem from debris in the meshwork building up and clogging normal drainage pathways. Natural cellular garbage disposal cells, called phagocytes, usually rid tissues of unwanted debris by gobbling it up. Could the blockage in the trabecular meshwork that appears to cause glaucoma be due to these cells not doing their job of riding the eye of debris? To explore this, researchers are seeing if there are fewer phagocytes in the trabecular meshwork of eyes removed from people with glaucoma

• DIABETIC RETINOPATHY

There is evidence in animals that an enzyme involved in the breakdown of glucose triggers an excessive buildup of faulty blood vessels in the retinas of people with diabetes, suggesting the possibility of using a drug that blocks the action of the enzyme to prevent or stymie diabetic retinopathy. Researchers are assessing the enzyme's production and function in the eyes of people with and without diabetic retinopathy.

- **CATARACTS** — One NDRI researcher has identified that some medicines, such as the statin drugs, cause cataracts in some animals but not in humans, while the reverse also occurs. An understanding of the similarities or differences in how various drugs act to cause cataracts in dogs, rats and humans may spur the development of new anti-cataract compounds and help predict which drugs are likely to cause cataracts in people.

► *Seeing through the Causes of Age-related Blindness continued*

Sieving. "The bottom line is that eyes of any age that a person is thoughtful and generous enough to donate posthumously will be well taken care of and highly valued," he added.

Since the early 1980's, NDRI has tried to meet the need for human eye tissue for research purposes by working closely with most eye banks throughout the country. Between 2002 and 2005, NDRI supplied more than 12,000 tissues to eye researchers, half of which were funded by the NEI. "Those of us who work on eyes and vision certainly value the materials that NDRI has provided us,"

"There are major diseases that affect the back of the eye and we would really benefit from having this part of the eye to study."

Dr. Paul Sieving, Director of the National Eye Institute

Dr. Sieving noted.

But NDRI fields more requests for research eye tissues than it can meet. About 38 percent of eye researchers need healthy retinal cells from young donors, but those tissues comprise only two percent of what eye banks offer NDRI.

"Today, most young donors are treated as cornea only donors in which only the cornea is surgically recovered," said Jeff Thomas, NDRI Director of Donor Services. "But it is the unused parts in the back of the eye from which researchers can learn the most about many of the major eye diseases that cause blindness with aging," Thomas added.

It's become increasingly difficult for researchers to gain access to whole eyes.

"There are major diseases that affect the back of the eye and we would really benefit from having this part of the eye to study," Dr. Sieving added.

You can help advance important eye research initiatives by contacting either David Pontino or Jeff Thomas at NDRI with referrals of potential eye tissue donors. Remember many people with eye diseases

can still donate for transplant and can also provide eye tissue useful to eye researchers if the eye bank recovers and shares the posterior pole. NDRI's experienced staff will coordinate the retrieval and transport of eye tissues to researchers. For more information contact 800-222-NDRI.

HOT TOPICS

Informed Consent:

Helping Families View Research as Opportunity vs. Option

It's well understood that the best time to make a decision about donating organs and tissue is not in the midst of a tragedy. But families most often face the choice for the first time when they are dealing with unimaginable grief.

"We are asking families to give something that is precious at a very challenging and stressful time," noted David Stiltner, MS, BCETS, Family Support Coordinator at LifeNet in Virginia. "The manner in which family members are treated will directly influence their grief for the rest of their lives."

So what is the best way to approach these families about the option to donate for research that does not compromise the integrity of either the research or cause additional grief?

"We treat every family with respect and compassion and support them during this difficult time while advocating for the opportunity in front of them, which is to donate and help others," said Kevin Myer, MSHA, CPTC, Executive Director for LifeNet.

LifeNet follows the guidelines for informed consent for organ and tissue donation that were adopted in 2000 by the American Association of Tissue Banks, the Association of Organ Procurement Organizations and the Eye Bank Association of America. (<http://www.aatb.org/model.htm>) These guidelines, which NDRI also adheres to, address the common concerns of families including assurances that their loved one's body will be treated with respect, donation will not affect funeral arrangements, and they won't be charged for costs related to donation.

The guidelines for research also require that families be told exactly which parts of the body can be donated, with the op-

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