Macular Degeneration

A Final Report of the Joint Interim Committee on Macular Degeneration

January 30, 2001

TO THE SPEAKER
OF THE
MISSOURI HOUSE OF REPRESENTATIVES
AND THE
PRESIDENT PRO TEMPORE
OF THE SENATE
OF THE NINETIETH GENERAL ASSEMBLY
OF THE STATE OF MISSOURI

Your Joint Interim Committee on Macular Degeneration
respectfully submits the following report:

Representative Harry Kennedy, Chair	Senator Harold Caskey, Chair
Representative Betty L. Thompson	Senator Jerry Howard
Representative Denny Meredith	Senator Mary Bland
Representative Sam Gaskill	Senator Marvin Singleton
Representative Larry Crawford	Senator Betty Sims

FINAL REPORT
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JOINT INTERIM COMMITTEE
ON
MACULAR DEGENERATION

COMMITTEE MEMBERS

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Joint Interim Committee on Macular Degeneration

The Joint Interim Committee on Macular Degeneration was established as a result of House Concurrent Resolution 4, which charged the committee to:

> ...make a comprehensive study on macular degeneration, including the solicitation of information from appropriate state agencies and the public on the social, economic, educational and health implications of macular degeneration.[1]

The committee examined the eye disease of macular degeneration for a number of reasons. First, in order to gain a greater understanding of the eye disease, the committee received testimony from various medical professionals which included ophthalmologists, an optometrist, an occupational therapist, a research professor of ophthalmology, representatives from the macular degeneration community, the Missouri Assistive Technology Advisory Council and a representative of the insurance industry. Second, the committee, along with the medical community was interested in raising greater community awareness of this eye disease. Third, in conjunction with increasing public awareness of macular degeneration, the committee wanted to examine the potential use of state appropriations in order to combat the incidence of the disease and to alleviate related problems suffered by Missourians.

After the committee was established, the committee held a hearing on macular degeneration December 7, 2000 at the University of Missouri-Kansas City. During the hearing, the committee heard testimony on various topics including general anatomy and physiology of the eye, information on some current surgical treatments for persons with macular degeneration, information on current visual rehabilitation strategies for persons with macular degeneration, clinical research issues on macular degeneration, information on insurance-related issues, and social support mechanisms for persons with macular degeneration. The committee

also received written testimony from medical professionals, members of the macular degeneration community and providers who could not attend the hearing.

Macular Degeneration and the Eye: Topical Anatomy and the Nature and Incidence of the Disease

General Anatomy and Physiology

Macular degeneration primarily affects the inner tissue of the eye, called the *macula*, which is centrally located on the *retina*. The *retina* is the nervous membrane located at the back of the eye which is responsible for receiving images of external objects which are refracted by the *lens*. The *retina*, which is connected to the *optic nerve*, contains 10 layers of nerve cells, including receptors called *rods* and *cones*. The *rods* are sensitive to the colors of white and black; the *cones* are sensitive to colors.

The *macula* provides individuals with sight in the center of their vision field and allows individuals to see fine details of objects (*i.e., visual acuity*) when focusing directly at an object. The ability to see fine details is necessary for a number of reasons including reading, driving, recognizing or distinguishing faces and completing work which requires the recognition of fine details. [2]

Age-related macular degeneration: United States and the state of Missouri.

Age-related macular degeneration (AMD) is one of the leading causes of vision loss in the United States and in Missouri. [3] It is reported that abnormalities associated with AMD affects about 8 million Americans over the age of 40 years old. A survey conducted in the United States estimated that 8% of persons aged 65 years to 74 years old are affected by AMD. It is also estimated that the incidence of the disorder increases to 15% among persons aged 75 years to 84 years of age.[4] Researchers have stated that about 200, 000 Americans are diagnosed annually with hemorrhagic AMD, or the wet form of this disease. [5]

In terms of racial and ethnic characteristics, White Americans are affected with AMD more than other ethnic groups. Further, it is expected that as the baby-boom generation reaches retirement age (persons born between 1946-1964), the number of persons with AMD will be 6.3 million persons.[6]

Data received from the Missouri Department of Social Services, Rehabilitation Services for the Blind estimated that the number of 40 year old or older White Americans and others in Missouri who are affected by visual impairments was 48, 632 persons. For African Americans in Missouri, the estimated number of visually impaired persons stood at 6,135. [7] It is important to state that the data containing the number of visually impaired persons is based on various factors contributing to visual impairments, which includes macular degeneration.

Macular Degeneration: Risk Factors, Types, Symptoms and Effects

Risk Factors

Although there is no specific cause of AMD, there are risk factors which can increase the incidence of the disease. Such risk factors associated with AMD include the lack of annual eye examinations for persons over the age of 50 -55 years by licensed ophthalmologists or optometrists, the race/ethnic background of the individual (White Americans have a higher incidence than African Americans), having light colored eyes or blue eyes, family history of the disease, smoking, hypertension (high blood pressure), high exposure of the eyes to the sun or ultra-violet rays, an inadequate diet which includes a low intake of leafy green vegetables (e.g., spinach, collard greens, kale) and fruits (which are a source of certain essential vitamins), a high intake of saturated fats and a lack of general exercise which can contribute to eye health and overall well being. [8]

Types of Macular Degeneration

There are two main types of age-related macular degeneration, *dry or the atrophic type* and *wet or the hemorrhagic type*. *Dry AMD* is the most common form of this disease and accounts for 90% of the AMD cases. The cause of this form of AMD is the atrophy (or the diminishing) of the *retinal pigment epithelial cells* of the *macula*. The atrophy of the *macula* is caused from yellowish build-up under the *macula* (called *drusen*) which results in the diminishing and drying out of the *macula*. This type of AMD develops slowly and usually causes mild vision loss such as a dimming of vision when reading. [9]

Wet, hemorrhagic AMD or exudative AMD is a greater threat to vision and accounts for 10% of the cases. In advanced stages, this form of macular degeneration causes rapid growth of small blood vessels beneath the *retina*. The affected blood vessels in turn, leak blood or other fluid resulting in the formation of scar tissue. This type of AMD can cause the creation of a large blind spot in the center of an individual's vision field and a marked loss of vision. [10]

Another type of macular degeneration is *juvenile macular degeneration (JMD).* *Juvenile macular degeneration* or *Stargardt's disease*, is a common form of inherited macular degeneration in persons under the age of 20 years who are diagnosed with this disease. Symptoms of this disorder include a loss in central vision. The underlying factors causing this disease (as revealed during an eye examination) include macular lesions surrounded by yellow-white flecks or spots. It has been stated that the progression of vision loss in persons with this type of macular degeneration is variable. Some research has indicated that this type of macular degeneration is uncommon and consist of various conditions. Each form of *juvenile macular degeneration* may have a separate prognosis and most types are not related to other conditions such as diabetes. [11]

Symptoms of Macular Degeneration

General symptoms of AMD include blurred or an absence of central vision; a wavy or bent appearance of straight lines on a page; dark or empty spaces blocking the central area of vision or fuzzy central vision. Researchers have stated that no pain is associated with AMD and that the disease develops over time and is frequently not noticed during the early stages. [12]

Effects of Macular Degeneration on Life Chances

The effect of AMD on the life chances of affected individuals undoubtedly causes a change in lifestyle and/or work. Due to a loss of central vision and the ability to focus on fine details (a loss of visual acuity), the Joint Interim Committee was informed that individuals have various problems including reading, writing checks and performing basic tasks such as cooking, managing their medications (if prescribed), driving and navigating through one's home. The committee also heard that the social-psychological effects of this disease on individuals who strive to maintain their independence can include isolation and depression.

The committee was informed by medical professionals, organizations, support groups and individuals with the disease that the best treatment approach is from a multi-disciplinary perspective. This approach would include the standard medical treatments, rehabilitative treatments and social-psychological treatments which

include services provided by social workers and psychologists.

Topical Review of Preventative and Treatment Regimens for Age-Related Macular Degeneration

Since the cause of AMD has not been determined and there is no cure for this disease, the degree of its effect on the life chances of individuals can vary. The committee received testimony (verbal and written) from medical professionals and members of the AMD community that there is no single treatment or preventative measure to combat this disease. As such, preventative measures and the treatment regimens presented to the committee can be categorized under three headings, *preventative, surgical and rehabilitative*. It should be mentioned that the discussion contained in this section is not exhaustive and that interested persons should contact the appropriate credentialed medical professionals who specialize in diagnosing and treating this disease.

Preventative

Routine Eye Examinations - certified eye care professionals (ophthalmologists and optometrists) agree that eye disease can occur at any age; in fact, it is reported that many eye diseases do not cause symptoms until the disease has caused damage to affected structures of the eye. Although individuals affected with AMD do experience certain symptoms, eye care professionals emphasize that early detection of AMD through eye examinations by certified eye care professionals is crucial so that the commencement of various medical treatments, rehabilitation and support services can have the greatest impact.[13]

Stop Smoking - some research has indicated that smokers are at a greater risk of developing macular degeneration than non-smokers. The committee was informed that research is mixed on this factor.

Controlling Hypertension - the committee was informed that controlling hypertension (high blood pressure) was important for treating macular degeneration. It has been well established that hypertension affects vital organs and blood vessels (including blood vessels inside the eyes) which can lead to visual problems.

Wearing Sunglasses - research has indicated that constant exposure of the eyes to ultra violet rays can damage the retina. This can increase the chances for intensifying the development of AMD.

Diet - eating a diet rich in vegetables and fruit and low in saturated fat has appeared to help individuals with AMD. Some research has found that vegetables such as spinach, kale and collard greens may be beneficial for lowering the risk of developing the wet form of AMD.

Anitoxidents/Carotenoids - recent research has revealed that persons who have taken *lutein* were more likely to reduce the risk of developing macular degeneration.

Regular Exercise - contributes to overall health of the human body.

Surgical and Other

Medical professionals repeatedly emphasized that none of the surgical treatment options presented during the interim hearing were perfect; in fact, some of the surgical treatments are still in the experimental stage. It has been reported that there is no proven cure or treatment for *dry* AMD. The committee was also reminded that a comprehensive examination of available treatments was not presented to the committee and that patient eligibility for a particular treatment is not guaranteed.

Some of the treatments include:

Laser Photocoagulation - for eligible patients, this method of treatment seals abnormal leaky blood vessels. However, the aging process may result in the growth of new blood vessels. Additional drawbacks include the loss of some vision as a result of the treatment (scotoma) or the eventual loss of central vision without the laser treatment.

Transcutaneous Electrical Stimulation of the Macula - the committee was informed that some patients benefitted from this treatment but care must be utilized with this form of treatment.

Transpapillary Thermotherapy - while this is used primarily for occular malignancies, this treatment option utilizes a red diode to treat poorly defined blood vessels. Clinical studies of this treatment option have shown some promise.

Macular Translocation Surgery - involves the moving of the *macula* away from abnormal blood vessels to a new area. The *retina* is either rotated around the optic nerve to a new location or it is displaced by a gas bubble. It has been reported that significant visual recovery was achieved in select cases, in spite of being associated with significant complications.

Laser Photodynamic Therapy - and the recent approval of *Visudyne* has shown some promise in the treatment of wet AMD. After a person is injected with a dye that is reactive to light, the dye passes through the body and pools in damaged blood vessels in the retina. A cold laser is used to seal off the leaking vessels. One side effect of this treatment is that since the dye remains in the body for several days, persons should avoid the sunlight (including avoiding the sunlight after receiving this treatment). If a patient is exposed to the sun, a sunburn can result.

<u>*Rehabilitative*</u>

If the loss in central vision cannot be corrected and results in a marked decrease in an individual's ability to perform daily functions, then rehabilitative services from an interdisciplinary approach should also be considered as an option to help maintain or restore independent living skills.[14]

Credentialed personnel who perform rehabilitative services include (1) occupational therapists; (2) orientation and mobility specialists; (3) rehabilitation teachers; (4) rehabilitation technology specialists; (5) low vision specialists; and (6) psychologists.

The types of rehabilitative services provided can include the following:

Low vision examinations and devices - which includes the use of hand-held magnifiers; high intensity lamps and other optical and non-optical aids which can help use the best of an individual's remaining vision;

Counseling and support groups - can aid an individual in adjusting to a loss of vision and can provide an individual with a community of persons with whom one can discuss similar problems and strategies of coping;

T*raining in adaptive techniques* - allows an individual with macular degeneration to obtain various skills which include home and personal management skills (meals preparation; personal care), communication skills (using large print; braille; screen magnification; telephones) and independent movement and travel skills (using a white cane; orientating an affected individual to a familiar and unfamiliar environment).[15]

Summary of Hearing

During the hearing, the Joint Interim Committee on Macular Degeneration was presented with various recommendations by medical professionals, providers, support group advocates and individuals of the macular degeneration community. After receiving the verbal and written testimony, the committee determined that common issues included the following:

Further Medical Research - During the hearing, committee members were informed that the exact cause of macular degeneration has not been determined. Also, there is currently no known cure for this disease. Having to consider these two crucial factors, the committee was reminded that continued medical research could lead to determining treatable causes of macular degeneration, the continual development of treatment regimens and refinement of current treatment regimens (including those treatments which are in various stages of development).

The committee was also presented with an option of contributing to the development of a research center on macular degeneration at a Missouri university which could facilitate the determination of factors which cause macular degeneration and the conduct of specialized research related to the disease.

Funding - is another important factor which is directly related to furthering medical research and improving patient access for treatment. The committee received written testimony from service providers who indicated that current state funding for the state's Rehabilitative Services for the Blind, Older Blind Services Program is inadequate for a growing number of individuals to purchase low vision aids and services. However, the committee cannot recommend an increase in funding for existing state programs which offer services to Missourians who suffer from AMD and other eye diseases. This is due to the current revenue shortfall for FY 2001 and FY 2002.

The committee was also informed that state funding could be used to establish a degree program at a Missouri university for trained rehabilitation

specialists such as vision specialists and to further the development and/or use of telemedicine in rural areas of the state.

Transportation - the committee was repeatedly informed that a lack of transportation existed, particularly in the rural areas of the state. The committee heard testimony that often, individuals affected with AMD were driven to appointments and other necessary destinations by their pastors or other members of their religious community. Other times, patients were responsible for finding their own transportation, which included using local taxi services (which became very expensive). The committee was reminded that a more effective mass transit system (which includes buses, trains, paratransit vans) could help minimize transportation problems for patients in metropolitan areas of the state.

In addition to utilizing the mass transit systems, members of the macular degeneration community and non-profit organizations should consider (if not considered) greater cooperation with the Missouri Department of Transportation, Division of Multimodal Operations. The Transit Division operates (in cooperation with the federal government) various programs including the Missouri Elderly and Handicapped Transportation Assistance Program and a federal/state capital and operating assistance program for smaller urbanized areas of the state. The assistance program includes two programs which transport elderly and disabled Missourians, OATS (Older Adults Transportation System) and SMTS (Southeast Missouri Transportation System).

OATS, or the Older Adults Transportation System (headquartered in Columbia, Missouri) and SMTS, or the Southeast Missouri Transportation System (headquartered in Fredericktown, Missouri) provide transportation to elderly Missourians as well as Missourians who have various disabilities. The service areas covered by OATS includes 87 counties (a majority of the state) and the service areas covered by SMTS includes 21 counties (primarily the southeast corner of the state and a few single county areas). Officials from both agencies stated that they receive funding and have contracts from

various state agencies which include the Missouri Department of Transportation, the Department of Social Services, Division of Medical Services and the Division of Aging, and the Department of Mental Health.

An official at the Missouri Department of Transportation did indicate in a post-interim committee meeting conversation that although the agency seeks to provide elderly Missourians and disabled Missourians around the state with quality transportation (given budgetary considerations), problems did arise when servicing Missourians with vision problems. In particular, the cost associated with servicing this population is increased due to providing transportation to a limited number of riders with varying work schedules and locations in a given area. This also increases the need for a number of vehicles in use during a scheduled day.

Therefore, the appropriate state agencies should review the service provided by transportation providers to ensure compliance with the needs of visually impaired Missourians. Due to current fiscal constraints, the committee cannot recommend at this time an increase in funding for state agencies which provide transportation to visually impaired Missourians.

Greater Public Awareness - of age related macular degeneration (AMD) was repeatedly presented to the committee. Proposals include (if not in existence) working with the Department of Elementary and Secondary Education in disseminating information on the importance of regular eye examinations by licensed medical professionals (ophthalmologists; optometrists) and disseminating information about the disease, especially the rarer form of *juvenile macular degeneration*.

The committee also received testimony that greater public awareness of this disease and available treatment options is needed for older Missouri residents, those providing care for older Missourians as well as eye care specialists in order to accurately document the incidence of this disease and to refer patients diagnosed with AMD to credentialed providers for appropriate medical treatments and rehabilitative services. This could consist of establishing or expanding an educational program in the Department of Social Services or Department of Health to fulfill this purpose.

Creation and/or Expansion of Existing Programs - the committee should examine the possibility of establishing a newborn vision screening program and/or increasing access to vision enhancement devices.

Recommendations

The Joint Interim Committee on Macular Degeneration makes the following recommendations:

(1) The Missouri Department of Health should initiate an educational program to make Missourians aware of the symptoms of macular degeneration, the legitimate treatments provided by certified medical professionals and encourage patients to seek further information, sound medical advice or a change in medical professionals if they feel that treatments are inadequate.

(2) The Coordinating Board for Higher Education should review and make recommendations for the establishment of a research center to further the study on the causes, nature, treatments and potential cure for macular degeneration.

(3) The Missouri Department of Transportation and the Department of Social Services, Division of Family Services, should review the services of all transportation providers to ensure that the needs of visually impaired Missourians are being adequately addressed across the state.

(4) The Department of Social Services, Rehabilitation Services for the Blind should continue to ensure that service providers comply with the requirements of service contacts awarded which include a testing requirement for braille instructors and orientation and mobility instructors and licensure by the medical professional's certifying board.

(5) Legislation should be introduced which establishes a newborn vision screening program or increased access to vision enhancement devices

Conclusion

The Joint Interim Committee on Macular Degeneration conducted this examination on the causes and incidence of macular degeneration with the anticipation that the contents contained herein will (1) encourage further medical research into this disease, and (2) lead to the development of proposed legislation which could address various issues related to the disease.

In closing, the Joint Interim Committee on Macular Degeneration would like to thank medical professionals, members of the macular degeneration community, service providers and state policy makers (past and present) for participating in the public hearing, providing verbal and written testimony and for facilitating discussions which could improve the life chances of individuals affected with macular degeneration in Missouri.

Appendix

Appendix A: House Concurrent Resolution 4

Whereas, macular degeneration is an eye disease that occurs when there are changes to the macula, which is a small portion of the retina that is located on the inside back layer of the eye, and results in a reduction of central vision and makes seeing details for close work, such as reading, difficult or impossible; and

Whereas, macular degeneration is the leading cause of blindness among older Americans, affecting ten million people today. The National Eye Institute estimates that the number could rise to eighteen million people by 2030; and

Whereas, there are two types of age-related macular degeneration. The wet form of macular degeneration, which involves only about ten percent of cases, responds to laser treatments in its early stages. The more common dry form is considered untreatable, although some recent research indicates that certain antioxidant vitamins and minerals may help prevent or slow its progression; and

Whereas, the exact cause of macular degeneration is unknown, but it may be related to aging, high blood pressure, smoking, and exposure to high levels of ultraviolet radiation and blue light, both found in sunlight; and

Whereas, ongoing research and studies have resulted in some encouraging early findings, such as the possible reversal of macular degeneration in its early stages; and

Whereas, the state of Missouri, through research, programs and funding, could facilitate the discovery and implementation of promising new treatments, technologies and programs for assistance for the benefit of those persons in the state who are afflicted with this disease:

Now, therefore, be it resolved by the members of the Missouri House of Representatives of the Ninetieth General Assembly, Second Regular Session, the Senate concurring therein, that a Joint Interim Committee of the General Assembly be created to be composed of five members of the House of Representatives, to be appointed by the Speaker of the House, with no more than three such members from the same political party, and five members of the Senate, appointed by the President Pro Tem of the Senate, with no more than three such members from the same political party, and that said committee be authorized to function during the interim between the Ninetieth and Ninety-first General Assemblies; and

Be it further resolved that said committee make a comprehensive study on macular degeneration, including the solicitation of information from appropriate state agencies and the public on the social, economic, educational and health implications of macular degeneration;

Be it further resolved that the committee be authorized to hold hearings as it deems advisable, and that the staffs of House Research, Senate Research and the Committee on Legislative Research provide such legal, research, clerical, technical and bill drafting services requested by the committee; and

Be it further resolved that the committee, its members, and any staff personnel assigned to the committee shall receive reimbursement for their actual and necessary expenses incurred in attending meetings of the

committee or any subcommittee thereof; and

Be it further resolved that the committee report its recommendations and findings to the Missouri General Assembly by January 1, 2001, and the authority of such committee shall terminate on December 31, 2000; and

Be it further resolved that the Chief Clerk of the of the Missouri House of Representatives be instructed to prepare properly inscribed copies of this resolution for the Speaker of the House of Representatives and the President Pro Tem of the Senate.

Offered by Representative Harry Kennedy

Anne C. Walker, Chief Clerk of the House, and Terry L. Spieler, Secretary of the Senate, do hereby certify that the aforementioned is a true and correct copy of House Concurrent Resolution No. , adopted by the House on , 2000, and concurred in the Senate on , 2000.

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Chief Clerk of the House of Representatives

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Secretary of the Senate

Endnotes

1. Legislature, House, *Joint Interim Committee on Macular Degeneration*, 90th General Assembly, 2nd sess., House Concurrent Resolution no. 4 (8 May 2000).

2. American Academy of Ophthalmology, *EyeNet: Eye Conditions & Diseases, What Is Macular Degeneration* (San Francisco: American Academy of Ophthalmology, 2000), 1. Website: www.eyenet.org.

3. Martin L. Katz, Ph.D., Letter to the Joint Interim Committee on Macular Degeneration, 7 December 2000.

4. Ibid.; Department of Social Services, Rehabilitation Services for the Blind, *Information Pertaining to Macular Degeneration,* (September, 2000), (Jefferson City).

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6. American Foundation for the Blind, *Living with Visual Impairment Caused by Age-Related Macular Degeneration: Fact Sheet,* (New York: American Foundation for the Blind, 2000), 2. Website: www.igc.apc.org/afb.

7. Department of Social Services, Rehabilitation Services for the Blind, *Macular Degeneration*. The data is based on the 1990 U.S. Census and statistical regression models which utilize statistical prediction.

8. Ibid.

9. American Foundation for the Blind, *Living with Visual Impairment*, 1.

10. Ibid.

11. Foundation Fighting Blindness, *Macular Degeneration*, (Hunt Valley: Foundation Fighting Blindness, 2000). Website: www.blindness.org; American Academy of Ophthalmology, *EyeNet: Eye Conditions & Diseases, Welcome to the Macular Degeneration Q & A Archive!* (San Francisco: American Academy of Ophthalmology, 2000), 4.

12. American Foundation for the Blind, *Living with Visual Impairment*; American Academy of Ophthalmology, *EyeNet: Eye Conditions & Diseases, What Is Macular Degeneration*, 1.

13. Department of Social Services, Rehabilitation Services for the Blind, *Information Pertaining to Macular Degeneration,* 1; American Academy of Ophthalmology, *EyeNet: Eye Conditions and Diseases, How Is Macular Degeneration Treated?* (San Francisco: American Academy of Ophthalmology, 2000).

14. American Foundation for the Blind, *Maintaining Your Independence: Fact Sheet,* (New York: American Foundation for the Blind, 2000).

15. Ibid.

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Missouri. Legislature. House. *Joint Interim Committee on Macular Degeneration.* 90th General Assembly., 2nd sess., House Concurrent Resolution no. 4 (8 May 2000).