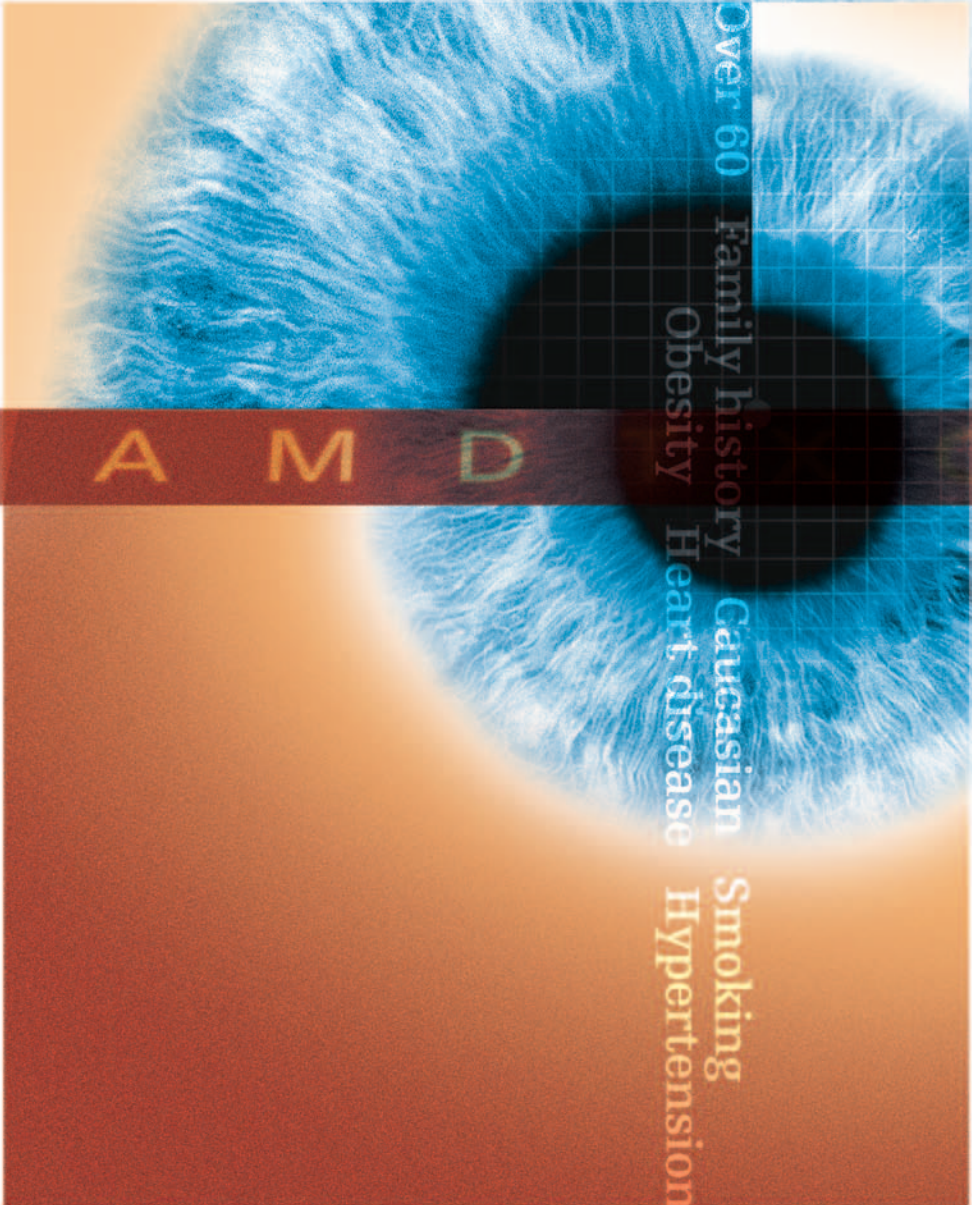


Resource Guide for Physicians and Staff

Beyond Diagnosis: Next Steps for People with AMD





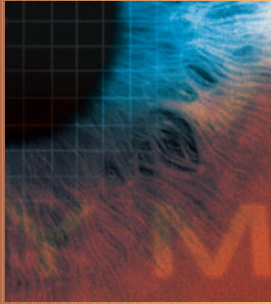
The Alliance for Aging Research extends its thanks to the following panel for reviewing these materials:

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Age-related Macular Degeneration

This resource guide is designed to inform you about the various services available to help your patients with AMD. The resources include information on rehabilitation, financial assistance, support groups, research, and employment options.

Organizations with Information on AMD and Eye Health

American Academy of Ophthalmology

www.aao.org

Represents board-certified ophthalmologists in the United States. This site provides eye health information through Medem, a network of leading medical societies. On Medem, the “Retina/Macula Problems” section contains information on AMD. Other topics include general and preventive eye care, low vision, and medical news.

American Health Assistance Foundation

www.ahaf.org

Funds research on age-related diseases, including AMD. This site provides information and resources for patients, caregivers, and loved ones. Look for a low vision resource list, as well as a newsletter on AMD and other patient education materials.

American Optometric Association

www.aoanet.org

Represents optometrists in the United States. Look under “Eye Conditions

and Concerns” for information on eye diseases like AMD, as well as low vision, and vision and nutrition.

Foundation Fighting Blindness

www.FightBlindness.org

Supports medical research on the preventions, treatments and cures of macular degeneration and other retinal degenerative diseases. Provides free information on these diseases, their causes, research, clinical trials and referrals to resources including physicians, low vision experts and assistive products and services. Publishes newsletters and coordinates a National Retinal Donor Program.

Lighthouse International

www.lighthouse.org

www.visionconnection.org

Provides information on vision impairment, a vision rehabilitation service locator (including low vision practitioners), and education materials for professionals and the public.

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Organizations Specializing in AMD

National Association for Visually Handicapped

www.navh.org

Provides information on low vision aids, as well as a “reading room” and links to resources for the visually impaired.

National Eye Institute

www.nei.nih.gov

Conducts and supports research on eye diseases and vision disorders. The “Health Information” section on this site has a portion devoted to AMD. There are also eye care resources, including eye health-related organizations, low vision resources, tips for finding an eye care professional, information on financial aid, and facts about clinical trials.

Prevent Blindness America

www.preventblindness.org

Offers programs and services to help fight blindness and save sight. Click on “Eye Problems” for a list that includes frequently asked questions about AMD, as well as information on growing older with good vision, detecting eye problems in adults, low vision, and questions to ask your eye care professional.

Research to Prevent Blindness, Inc.

www.rpbusa.org

Supports research on AMD and other blinding eye diseases. Look under “Quick Links to Eye Disorders” for brochures, articles, and other information on AMD.

AMD Alliance International

www.amdalliance.org

This site provides facts about AMD, as well as information on prevention, treatment, research, rehabilitation, and support services.

Macular Degeneration Foundation

www.eyesight.org

Under the “Table of Contents” section of this site, you can easily search through a range of topics, including research, glossary of terms, news, and links to other organizations. Each “Chapter” also includes personal stories.

Macular Degeneration Partnership

www.amd.org

This site has a section on general information about AMD (what it is, who gets it and what people with the condition can do), a newsletter, and a section on current research. There is also a daily AMD update on the main page.

Employment Agencies for the Visually Impaired

Job Accommodation Network

P.O. Box 6080
Morgantown, WV 26506-6080
1-800-526-7234
<http://janweb.icdi.wvu.edu>
A free service of the Office of Disability Employment Policy, this organization provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities.

Job Opportunities for the Blind National Federation of the Blind

1800 Johnson Street
Baltimore, MD 21230
(410) 659-9314
www.nfb.org/jobpaths.htm
Job Opportunities for the Blind has training centers in Colorado, Minnesota, and Louisiana, as well as a service called America's Jobline. Developed by the National Federation of the Blind, the jobline helps access job listings and computer services with the use of a touch-tone phone.

American Foundation for the Blind AFB Career Connect

11 Penn Plaza, Suite 300
New York, NY 10001
1-800-232-5463
(212) 502-7600
www.afb.org
The American Foundation for the Blind offers a service called AFB CareerConnect, a free resource for people to learn about the range and diversity of jobs that are performed throughout the United States and Canada by adults who are blind or visually impaired.

Blinded Veterans Association

477 H Street, NW
Washington, DC 20001
1-800-669-7079
(202) 371-8888
www.bva.org
The major focus of the Blinded Veterans Association (BVA) is its Field Service Program, which enables blind veterans to travel across the country to talk to and act as role models for other blind veterans. The BVA Field Service representatives can link blind veterans with services, rehabilitation training, and other benefits that are available to them. Representatives can also help fellow veterans find jobs.

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Financial Support

EyeCare America Seniors EyeCare Program

1-800-222-3937

www.eyecareamerica.org

Coordinated by the American Academy of Ophthalmology (AAO), this program provides free and low-cost eye exams for US citizens age 65 and older who have not seen an eye care professional in 3 years.

VISION USA

1-800-766-4466

www.aoanet.org

Coordinated by the American Optometric Association (AOA), this program provides free eye care to uninsured, low-income workers, and their families.

Lions Clubs International

300 West 22nd Street

Oak Brook, IL 60523-8842

(630) 571-5466

www.lionsclubs.org

Provides financial assistance to individuals for eye care through local clubs. Check your phone book for one in your area. The Lions Club has several outreach and prevention programs. Lions are recognized worldwide for their service to the blind and the visually impaired.

Knights Templar Eye Foundation

5097 North Elston Avenue, Suite 100

Chicago, IL 60630-2460

(773) 205-3838

www.knightstemplar.org/ktef

Provides assistance for eye surgery to people who are unable to pay or receive adequate assistance from current government agencies or similar sources. The Knights Templar also organize fundraising activities and raise money for medical research and educational assistance. Their Eye Foundation is a charity that provides research, surgical treatment, and hospitalization to those who suffer from eye disease.

Directories

American Foundation for the Blind

11 Penn Plaza, Suite 300
New York, NY 10001
1-800-232-5463
(212) 502-7600

www.afb.org/services.asp

This online directory can help locate organizations that provide services to the blind or visually impaired and their families. You can use the directory to find a service provider by name, state, or service category.

Lighthouse International

111 East 59th Street
New York, NY 10022-1202
1-800-829-0500
(212) 821-9200

info@lighthouse.org

www.lighthouse.org

www.visionconnection.org

Lighthouse International offers information on vision impairment, a vision rehabilitation service locator (including low vision practitioners), and education materials for professionals and the public. Access via web, email, phone, or mail.

Rehabilitation for Patients

A key rehabilitation tool for patients is vision rehabilitation instruction. Through this instruction, an individual with vision loss or impairment can be taught how to do things to make everyday living easier, such as marking clothes, groceries, and medications so that they can be found easily, modifying the home for safety and comfort, and improving lighting and reducing glare. The following organizations provide information that can help.

American Council of the Blind

1155 15th Street, NW, Suite 1004
Washington, DC 20005
1-800-424-8666
(202) 467-5081

www.acb.org

Serves as a national clearinghouse on blindness issues for individuals, organizations, and institutions. Publishes *The Braille Forum*, a free monthly national magazine.

American Foundation for the Blind

11 Penn Plaza, Suite 300
New York, NY 10001
1-800-232-5463
(212) 502-7600

www.afb.org

Serves as a one-stop information and referral resource for people who are blind or visually impaired, the people who work with them, and the general public. Offers consultation services to eye care, rehabilitation, and education professionals. Provides referrals to low vision centers.

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Associated Services for the Blind

919 Walnut Street, 2nd Floor
Philadelphia, PA 19107
(215) 627-0600
www.asb.org

Offers training on personal adjustment to blindness, as well as orientation and mobility. Provides materials in Braille. Offers computer training using adaptive devices.

Independent Living Services for Older Individuals Who Are Blind

U.S. Department of Education, OSERS
400 Maryland Avenue, SW
Room 3326, MES
Washington, DC 20202-2741
(202) 205-9362
www.ed.gov/programs/rsailob/index.html

Provides training in skills of routine daily living, travel, communication, provision of adaptive devices, low vision services, family and peer counseling, and community integration such as outreach, information and referral. Funded through Title VII, Chapter 2 of the Rehabilitation Act. Programs are available in every state and accessible through each state agency for the blind.

National Federation of the Blind

1800 Johnson Street
Baltimore, MD 21230
(410) 659-9314
www.nfb.org

Provides a wide variety of services to visually impaired people.

VISIONS/Services for the Blind and Visually Impaired

500 Greenwich Street, 3rd Floor
New York, NY 10013-1354
1-888-245-8333
(212) 625-1616
www.visionsvcb.org

Offers free services to adults over age 55 and teens with severe vision problems. Services include self-help study kits, counseling, vision rehabilitation training, consumer workshops, and an information center.

Support Groups

The organizations listed below have support groups for people living with macular degeneration.

Association for Macular Diseases, Inc.

210 East 64th Street
New York, NY 10021
(212) 605-3719

Council of Citizens with Low Vision International

1859 N. Washington Avenue, Suite 2000
Clearwater, FL 33755-1862
1-800-733-2258
www.cclvi.org

Lighthouse International

111 East 59th Street
New York, NY 10022-1202
1-800-829-0500
(212) 821-9200
www.lighthouse.org

National Association for Visually Handicapped

22 W. 21st Street, 6th Floor
New York, NY 10010
(212) 889-3141
(212) 255-2804
www.navh.org

Macular Degeneration Foundation

P.O. Box 531313
Henderson, NV 89053
1-888-633-3937
(408) 260-1336
www.eyesight.org

Research

There is currently some exciting and promising research being conducted on various stages of AMD. The National Eye Institute and ClinicalTrials.gov are excellent resources for finding out where clinical trials are being conducted, who can participate, and the results of completed studies.

NEI Clinical Studies Database

www.nei.nih.gov/neitrials
This database contains information on clinical studies, both ongoing and completed, that have been conducted and supported by the National Eye Institute (NEI) since 1970.

ClinicalTrials.gov

www.clinicaltrials.gov
You can search by disease, location, or sponsor, and participate in current research.

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Print, Audio, and Video Materials

American Printing House for the Blind

1839 Frankfort Avenue
P.O. Box 6085
Louisville, KY 40206-0085
1-800-223-1839
(502) 895-2405
www.aph.org

Provides free subscriptions to *Reader's Digest* and *Newsweek* on disposable audiocassettes. Provides *Reader's Digest* in Braille.

Braille Circulating Library, Inc.

2700 Stuart Avenue
Richmond, VA 23220
(804) 359-3771
(804) 359-3743

Loans Braille materials, talking books, audiocassettes, and large print Christian materials.

Choice Magazine Listening

85 Channel Drive
Port Washington, NY 11050
(516) 883-8280

www.choicemagazinelisting.org
Selects and records memorable writing from over 100 leading magazines. Every other month, this free service offers its subscribers eight hours of outstanding unabridged articles, fiction, and poetry read by professional voices and recorded on four-track cassette tapes. The required four-track player is provided free of

charge by the Library of Congress through its Talking Book program, which is available to those who are unable to read because of visual or physical handicap.

Christian Record Services, Inc.

4444 South 52nd Street
Lincoln, NE 68516-1302
(412) 488-0981

www.christianrecord.org

Provides books and magazines in Braille, large print, and audio cassette.

Gold Violin

1-877-648-8400

www.goldviolin.com

In partnership with Lighthouse International, the Gold Violin features select products that are helpful to people with vision problems.

Jewish Braille Institute of America

110 East 30th Street
New York, NY 10016
1-800-433-1531

(212) 889-2525

www.jewishbraille.org

Provides books of Jewish interest on audio cassette, in Braille, and in large print. They are available to anyone who is blind, visually impaired, or physically or learning disabled. All services are free of charge.

National Library Service for the Blind and Physically Handicapped

Library of Congress
 1291 Taylor Street, NW
 Washington, DC 20011
 1-800-424-8567
 (202) 707-5100
 (202) 707-0744 (TDD)
www.loc.gov/nls

Provides a free library service to individuals with visual impairments. Offers Braille and large print materials, as well as recorded books and periodicals.

New York Times/Large Type Weekly

229 W. 43rd Street
 New York, NY 10036
 1-800-631-2580
 (212) 556-1234
www.nytimes.com/nytimestore/publications

The *New York Times Large Type Weekly* was developed especially for people with low vision. It offers a select package of the week's news printed in 16-point type—about twice the size of the regular type. Sections include world and national news, health, business, the arts, sports, and the *New York Times* crossword puzzle.

Reader's Digest Large Print Publications

1-800-431-1246
www.rd.com/store/department.jhtml?categoryId=2
www.rd.com/partnersforsight

Reader's Digest offers a large print version of the magazine. The Reader's Digest Partners for Sight Foundation offers large print publications, including fiction, mystery, biography, and adventure.

Recording for the Blind and Dyslexic

20 Roszel Road
 Princeton, NJ 08540
 1-800-221-4792
 (609) 520-8031
www.rfbd.org

Provides recorded books, textbooks, and materials needed for occupational pursuits.

Talking Tapes/Textbooks on Tape

16 Sunnen Drive, Suite 162
 St. Louis, MO 63143
 1-877-926-0500
 (314) 646-0500
www.talkingtapes.org

Provides textbooks, novels, and other materials on cassette tapes to those who have difficulty reading due to visual, physical, cognitive, or learning disabilities.

Xavier Society for the Blind

154 East 23rd Street
 New York, NY 10010-4595
 1-800-637-9193
 (212) 473-7800

Catholic lending library that provides free, English language books and religious material in large print, Braille, and audio formats.

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2021 K Street , NW, Suite 305
Washington, DC 20006
T 202.293.2856
F 202.785.8574

www.agingresearch.org

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