International Advocacy Handbook

Tools to influence vision research funding

by James Jorkasky, National Alliance for Eye and Vision Research

ARVO®
The Association for Research
in Vision and Ophthalmology

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Please visit www.arvo.org/advocacy for PDF copies of this handbook and related materials.

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Preamble: Using this handbook

"Advocacy" is a way to influence a decision that is favorable to you. For the ARVO community, advocacy is used primarily to increase eye and vision research funding.

In the United States (US), ARVO has engaged in many NAEVR advocacy activities to expand awareness of eye disease and vision impairment and to increase vision research funding. ARVO offers this handbook to members and others to help increase vision research funding worldwide. This publication presents potential advocacy activities and accompanying examples (highlighted in the text and included in the appendices). These examples are not meant to "export" a specific US-style of advocacy, but are presented as information for the reader to consider in establishing or expanding vision research advocacy activities in their home country or region, whether as an individual effort or through collaboration with fellow researchers or vision-related educational or patient organizations.

ARVO prepared this handbook using these assumptions:

- **ARVO is extremely sensitive to and respectful of the vast cultural differences among its membership**, especially as they relate to political systems and ways to communicate. The examples used may provide a basis to develop activities that best influence research funding within the home country or region.

- Advocacy by its very nature involves education. This publication's examples can be used to establish or expand educational programs on the value of vision research, even if they are not used specifically to influence funding decisions.

- Advocacy programs can influence decision-makers in both public and private funding organizations in the home country or region, as well as international funding organizations.

- As many countries are just embarking on advocacy programs ─ whether to establish national funding entities or to encourage increased funding by existing public or private sources ─ these examples can be tailored to address a specific purpose.

- The vision health message is broad, encompassing research, prevention, diagnosis and treatment, rehabilitation, access to healthcare, quality of life and economic burden. This handbook focuses on advocacy for eye and vision research funding.

- Before an individual engages in advocacy, he/she should determine whether this activity is permitted within his/her terms of employment, especially if he/she is affiliated with a publicly funded academic institution or serves as a government advisor.

- If a group of researchers forms a home-country/region organization devoted to vision research advocacy, they should understand and comply with government regulations, especially if contributions are solicited.

Preparation is key to effective education and advocacy. This document first identifies how advocacy can be used and then considers the components of developing and sharing an advocacy message, such as:

- **Who** will be the target of your message (ranging from an individual to the general public)?
- **What** are your advocacy messages and what are the core components?
- **When** should advocacy messages be used, (ranging from certain times in the budget/funding cycle to an ongoing program of education and advocacy)?
- **Where** can your advocacy messages be used (ranging from written and electronic communications to press and public events)?

The "Advocacy in action" section focuses on **how** to share your message, which includes some helpful hints about the mechanics of message delivery.

Some phrases have been abbreviated.

- "Vision research" implies "eye and vision research"
- "Eye disease" implies "vision impairment and eye disease"
- "Press" implies a variety of written and electronic media
- "NEI" refers to the National Eye Institute within the US National Institutes of Health (NIH)
- "Coalition partners" is a term that refers to organizations with which you can work collaboratively to expand your advocacy message. These can be educational foundations or patient organizations, whether devoted solely to vision issues, chronic disease issues, (for example, diabetes) or social/gender/aging/ethnic diversity issues.

Introduction: An invitation to advocacy

As noted in the Preamble, "advocacy" is used to influence a decision that is favorable to you. Advocacy for vision research funding can be

- conducted as a formal and/or informal effort.
- conducted as a one-on-one and/or group effort. The latter engages fellow researchers or other organizations interested in vision health issues, such as vision advocacy or patient organizations or advocacy groups with similar interests (aging, ethnic health or vision health implications of chronic diseases, such as diabetes).
- focused on support from home country/region public or private entities and/or international public or private funding entities — or a combination.
- engaged in a wide range of communications, including personal letters and visits; formal testimony and position papers; fact sheets; educational and advocacy events; and press releases geared toward educating the public and expanding the community of support for vision research funding.

Why advocate for vision research funding?

Expand education and awareness

- **Incidence of eye disease.** This can be expressed in both current and future statistics that include the impact of changing demographic factors, such as aging of the population; increasing ethic diversity; nutrition and lifestyle (obesity, stress, smoking); environmental hazards (e.g., air/water/sunlight); and economy/workplace factors (such as change from an agricultural to an industrial or service-based economy).
- **Economic and social burden of eye disease.** This can be expressed in both quantitative and qualitative terms, such as direct and indirect healthcare costs; impact on productivity, independence and quality of life; and impact on regional and global competitiveness.
- **Vision needs that are still unmet.** Based on the factors cited above. Such a quantitative and qualitative assessment can be used to identify the adequacy of the country's vision health care/social services system, from research to diagnosis and treatment, rehabilitation, productivity and quality of life.
- **Current and needed eye disease prevention, diagnosis, treatment and rehabilitation programs.** Increasing awareness of existing programs not only benefits individuals, but serves as a basis to identify additional needs that may be met through public and/or private support.

Build public demand that can influence government support

- **Adequacy of current government investment in vision.** Includes funding for assessing the country's vision health and its impact on the economy; funding for basic and translational vision research; funding for vision prevention, diagnosis, treatment and

rehabilitation programs; adequacy of vision care in the country, whether in public or private healthcare settings; and access to care issues.

- **Adequacy of the vision research/vision care scientific infrastructure.** Evaluates the country's system for training and funding researchers and whether its vision health system relies on the application of research from outside the country.
- **Assist the government in identifying vision priorities** by emphasizing the importance of research funding to the ultimate effort to prevent eye disease and to save and restore vision.
- **Emphasize the cost-effectiveness of vision research** to assess if investment in vision research can delay, save or prevent direct and indirect healthcare expenditures, as well as improve the quality of life.

Example: Appendix A
On April 23, 2008, ARVO provided testimony to the US Senate Labor, Health and Human Services and Education (LHHS) Appropriations Subcommittee (with jurisdiction over NIH funding) that emphasized the chilling effect on young investigators and clinician scientists in vision research due to flat NEI funding during the past five funding cycles.

Build private vision research funding support

- **Gain credibility with private funding sources.** They may be more likely to consider funding vision programs that are supported by well-documented examples of need within the country.
- **Gain credibility with potential advocacy partners.** This includes those that may not be vision-focused, but have an interest in some aspect of health or demographic trends related to it, for example, organizations related to aging, ethnicity, gender health or specific chronic diseases, such as diabetes.

Expand sphere of influence and foster collaboration

Whatever resources are available for an advocacy program, a well designed effort can bring focus and credibility to an issue domestically and internationally, thereby expanding the sphere of influence and potentially engaging the collaborative efforts of other organizations.

Developing and implementing an advocacy plan

To achieve your goal, you need to develop a well designed advocacy program. This involves answering four simple questions:

- **Who** will be the target of your message (ranging from an individual to the general public)?
- **What** are your advocacy messages and what are the core components?
- **When** should advocacy messages be used, (ranging from certain times in the budget/funding cycle to an ongoing program of education and advocacy)?
- **Where** can your advocacy messages be used (ranging from written and electronic communications to press and public events)?

Who? Advocacy targets

First, an advocacy program must identify targets ─ who are you attempting to influence and what is the most appropriate way to reach that target (whether it is an individual, a governing body, an academic institution, a philanthropic board, etc.)?

Government / public funding sources

A. **Home country public sources** could include members of a legislative body, executive branch officials (ministries of health, education, aging, defense, etc.), a specific government health or research agency, government regulators and payers or academic institution officials (if a publicly-funded academic institution). Note that staff members are often just as important (if not more so) than the individual you are attempting to influence. For each of these, you should consider several questions.

Legislators

- What is the process by which legislative decisions regarding nationally funded vision research are made? For example, how is the national budget developed and how are decisions made regarding vision research spending ─ whether from a health or education budget? Is the legislative body the primary advocacy target?
- Are there dedicated committees and staffs that develop budget and spending recommendations? How does an individual or organization provide input into that process, whether informally or formally? Do the legislators take their guidance from these committees, or do they exercise discretion? Are these committees a primary or secondary advocacy target?
- What are the deadlines and filing requirements for making budget requests? What is the required format and content of such requests? What are the key times to influence the process? (See When? section below.)
- Consider how you can position your activities so you are seen as assisting the process and improving the outcome, especially with respect to the country's vision health care

system. One way to establish credibility is to volunteer to serve on a government-sponsored committee or task force in the health arena.

Executive branch officials/ministries (health/social programs, education, defense, aging)

- What degree of influence and discretion does the executive branch/ministry official have with respect to budget and spending? Do they merely implement programs? Do they use their positions to influence decisions, even if funding is ultimately determined by legislators?

Example: Appendix B
Since the Fiscal Year 2006 funding cycle, NAEVR has advocated for defense-related eye and vision research, specifically that it remain eligible for peer reviewed funding through the Department of Defense (DOD) Peer Reviewed Medical Research Program (PRMRP).

- Is this government department or individual a primary or secondary advocacy target? Even if an official cannot directly influence the budget process, he/she may influence public opinion on health and social programs.
- Are there key defense programs related to vision, which is vital to direct battlefield and combat-support functions? Is this a potential source of funding?

Government health or research agency, government regulators/payers

- What degree of influence and discretion do individuals at the government agencies with jurisdiction over health have (for example, health care or health research agency or the health care products regulatory and payment agencies)? Is there much discretion, or do they merely implement programs?
- Is this government department or individual a primary or secondary advocacy target? Even if an official cannot directly influence the budget process, he/she can influence public opinion on health and social programs and therefore might be an important target. For example, can the results of vision research affect faster ophthalmic product approvals?
- Especially if these government programs are cash-strapped, consider how well-developed incidence and economic burden data can assist these officials to better understand where an investment in vision research can ultimately improve the quality of life and prevent, delay or save costs.

Example: Appendix C
On March 13-14, 2008, NAEVR joined with ARVO in conducting a joint meeting between the NEI and the US Food and Drug Administration to consider alternative endpoints in clinical trials for new glaucoma drug therapies and devices. NAEVR also followed up with letters to the Directors of the NIH and FDA, as well as to the US Congress, emphasizing the cost-effectiveness of vision research in potentially reducing the time/cost of clinical trials and expediting new products to patients.

Academic institution officials

- Determine if research funding is prioritized and managed at a centralized or decentralized level, and target appropriately with a message about the value of vision research.
- As appropriate, note the collaborative nature of vision research with other key research areas, not only to seek funding but to demonstrate the cost-effectiveness of the research.

B. Regional government/multi-country alliance public funding sources

The best example of this may be the European Union and whether it plans to fund health and social programs that affect its membership broadly. If it provides funding for programs that address the aging population, developing an advocacy message about the impact of aging on vision may assist in securing research funding.

The questions posed so far as to the process and primary and secondary targets of advocacy also apply in this case, especially for understanding how to identify and influence the individuals and/or committees involved in decision-making.

C. International public funding sources

Because organizations such as the World Health Organization and UNICEF are inherently tied to multi-government funding, they could potentially serve as a source of funding as well as key data (for example, incidence and economic burden), collaboration and information exchanges that can strengthen your advocacy message. Participating in committees associated with these organizations can facilitate opportunities to benchmark with representatives from other countries on effective advocacy programs, just as there are at the ARVO and International Agency for the Prevention of Blindness (IAPB) Annual meetings.

The questions presented in Section A above also apply in this case, especially to increase understanding of the process and identify the individuals involved in decision-making.

Example

The best example of a one-on-one government exchange may be the ARVO-Indo Collaborative Research Program, an effort between the NEI and the Indian government to increase funding for vision research. In summary, ARVO received funding from an NEI cooperative agreement grant to hold two conferences aimed at increasing collaboration between US and Indian vision researchers. This ongoing project, which includes a Joint Working Group and a session at the ARVO Annual Meeting, also provides grants funded cooperatively between the two countries. Note: Even if collaborations with another country's vision research public funding source may not yield significant financial resources, it could yield potentially valuable incidence data, translational research opportunities and useful training exchanges.

Private vision research funding sources

A. Private home-country sources

The same process for identifying targets for advocacy in the public funding sector apply to the private sector. These include private academic institutions, philanthropic foundations and patient advocacy organizations. The latter may focus on vision-related issues, chronic diseases that impact vision health (for example, diabetes) or on age/gender/ethnic diversity health issues. Even if vision research funding is not currently directly available from an organization, it is worthwhile sharing an advocacy message and developing collaborations that may build toward available resources.

B. Private international funding sources

Similarly, numerous international philanthropic foundations and patient advocacy organizations may have a presence in the home country or provide funding opportunities from their headquarters. These include those dedicated to vision (for example, the Lions Clubs International) and those that fund research into chronic diseases that impact vision (for example, Juvenile Diabetes Research Foundation International).

C. Corporate funding from home-country and/or international sources

Corporate funding/partnerships can be important in developing both educational and advocacy programs that can range from evaluating the incidence of eye disease/unmet need to direct funding for research. Corporate partners can be helpful in advocacy communications with governmental representatives, as they can emphasize that private funding for research may not be adequate in that country/region, necessitating the need for public funding.

What? Advocacy messages and their components

Just as important as your advocacy target is your message. Determining that message for the appropriate audience and "staying on message" with a busy legislator or executive official is not always easy.

A. How encompassing is your message?

The vision health message is broad, encompassing research, prevention, diagnosis and treatment, rehabilitation, access to healthcare, quality of life and impact/economic burden. Although each area can support its own series of advocacy messages, they are often synergistic and assist the recipient to better understand the full context. This section focuses on the eye and vision research funding message.

Example: Appendix D

NAEVR's request to the US Congress for Fiscal Year 2009 funding of $31 billion and $711 million, respectively, for the NIH and NEI, presents various messages, as does the accompanying Talking Points document. These documents "stay on message" about the importance of increased vision research funding.

B. Message development components

Below are components of a comprehensive "value of vision research " message. These could apply to verbal and accompanying written documents, such as a letter, position paper and talking points, formal testimony, a fact sheet or a summary of an educational or advocacy briefing event.

- **The request,** which should be simple and stated clearly. For example, "The government should fund vision research at a certain amount in a specific budget cycle."
- **Impact of eye disease,** including current and future incidence data and demographic trends; impact on key populations (age, gender, ethnicity); impact from other chronic diseases
- **Impact of eye disease/locally or regionally**, including data on the district or region which the recipient represents
- **Impact of eye disease on patients,** including a description of daily life challenges, quality of life and impact on family. Patients can often be the most effective advocates, so consider how to engage them ─ directly in visits or in providing verbal or written testimony.
- **Economic and societal burden**, including direct and indirect health care costs; impact on productivity, independence and quality of life; and impact on families
- **Public opinion data about vision loss,** such as the results of studies about the value of sight (including those from other countries)
- **Current spending on vision research versus other diseases, especially compared with economic burden,** including per capita investment and amount spent on vision as a percent of the economic burden
- **Specific examples of vision research, especially research conducted locally/regionally,** that may have major international consequences.
- **Value/cost-effectiveness of breakthroughs emerging from research,** including a qualitative discussion of the research and any quantitative data on its impact (e.g. reduced government disability payments)
- **Missed opportunities, due to inadequate funding**, such as failure to follow up on past research findings (in the home country or internationally), as well as to pursue a new avenue of vision research based on a greater understanding of biological systems.
- **Impact on the vision research infrastructure**, including whether sufficient numbers of new investigators are being trained and if the country must rely on scientists trained abroad.
- **Why private funding is inadequate and federal funding is necessary**, to ensure that the recipient understands that if research is not funded by the government, it may not get done.

Example: Appendix E

In 2008, NAEVR and coalition partner Research!America released an updated version of a fact sheet first published in 2005 that illustrates how investment in vision research saves lives and money.

C. Message development: Formal argument and personal story approaches

A well-developed advocacy message tells a story. The more that the recipient connects with and responds to that story, the more successful it is. It can be a "formal argument," presenting a series of metrics, such as incidence and cost of eye disease or percent of budget spent on vision research, or it can be a "personal story" (as noted above) from a patient. Both are valid messages and can be used together to establish a quantitative case (incidence, cost) and provide a qualitative or empathetic context (patients can no longer take care of themselves). Your strategy depends on the research that you do before an advocacy visit. If you discover, for example, that the recipient has a family member with eye disease, he/she will already have a personal connection to this issue, paving the way for a more quantitative discussion**.**

D. Targeting your message

Your message depends on what you know about the recipient.

- **Personal experience with vision loss:** Learn what you can about the individual and whether they or a family member has a personal connection to vision issues (as noted in the "personal story" above).
- **Home country region or district**: Be able to describe the research and the researchers conducting it at the institution in the message recipient's district. Let the recipient know if this is breakthrough research that is drawing international attention. Note the inclusion of regional research references in the message section above.
- **Educational experience:** Understand how a recipient approaches decision-making based on his/her educational background (for example, are they a health care provider, an economist, an academician, a lawyer, a life-long politician). Focus on the message components most likely to appeal to them.
- **Political affiliation and key issues:** Understand the recipient's political affiliation and what that party stands for (for example, health care, social programs, economics, competitiveness), as well as the recipient's history on key issues, specifically support for research and education.

E. The patient's message

A patient's testimonial can be influential, whether it is given directly in visits or in verbal and written testimony. Patients should describe the impact of eye disease on their lives and how research could potentially save/restore their vision and improve quality of life. Be prepared to supplement patient testimonial with facts and figures from your message that support the funding request.

Example: Appendix F

Every year, Prevent Blindness America (PBA) conducts an Advocacy Day that engages patients, ranging from children to adults, who share their personal experiences with vision loss. PBA covers the expenses associated with these advocates' travel to ensure that they can participate in this event.

When? Timing advocacy messages

Advocacy for vision research funding should continue throughout the year as you build awareness with your colleagues, coalition partners and the media. However, it is important to understand all opportunities within the home country's budget planning and development cycle ─ both formal and informal opportunities to influence the process. Some considerations include:

Example: Appendix G
On January 25, 2008, NAEVR hosted an Advocacy Day by the ARVO Program Committee just as the US Congress was to begin its Fiscal Year 2009 budget and appropriations process. Many offices noted that the vision research community was among the first advocacy groups to present a funding recommendation for the NIH. For ARVO member Dr. Linda McLoon (University of Minnesota), it was an opportunity to visit with the Washington-DC-based staff of offices that she had hosted in her laboratory in late 2007.

- **What is the budget cycle?** Is it yearly, or is there multi-year funding for all or specific programs?
- **What steps are there to the budget cycle?** Do various government departments develop funding recommendations which are then presented to the legislative or executive body? Are there public events at which to provide testimony, such as committee meetings or specific hearings on the budget priorities? Are there also private opportunities to meet with legislators or ministry officials?
- **Consider whether a group advocacy effort can be effective,** in addition to one-on-one activities. This could be with fellow researchers ─ either those in vision or in other areas of science ─ or with home-country vision-related organizations or patient advocacy organizations.
- **Consider organizing a day or week of events that expand awareness of eye disease, either dedicated to the home country or as part of an international effort.** Examples include the global AMD Awareness Week held each September, the first-ever World Glaucoma Day, held on March 6, 2008 or the US-based Healthy Vision Month held each May. These targeted events can reflect home-country vision issues, and if held in conjunction with international events, can amplify the value message of vision research. Note that home-country or international events on broader health issues conducted with coalition partners or collaborating organizations also provide an opportunity to feature the vision-impact message (for example, aging, ethic or gender health-specific impact of a chronic disease, such as diabetes.)

Example: Appendix H
On March 6, 2008, for the first-ever World Glaucoma Day (WGD), NAEVR assisted the American Glaucoma Society in conducting an advocacy day and glaucoma screening event on Capitol Hill that included more than 100 visits with Members of the US Congress. AGS/NAEVR also worked with key Democratic and Republican Members of the US House of Representatives to sponsor a House Resolution acknowledging March 6, 2008, as World Glaucoma Day.

Example: Appendix I
World Sight Day (WSD) will be held on October 9, 2008. WSD, an annual day of awareness about blindness and vision impairment, is coordinated by IAPB under the *VISION 2020 Global Initiative.*

Example
The AMD Alliance International organizes an AMD Week in September each year. As noted in Appendix (cited on Handbook page 15), NAEVR focused its AMD Week event to release *The Silver Book: Vision Loss.*

Where? Advocacy message routes

The more exposure your message has, the better chance you have to develop support for your goals. Whether you are working independently or as part of a group, consider a comprehensive campaign to amplify your message and its impact. A campaign might include:

- visiting a governmental official.
- hosting a government official at your academic institution, especially in your laboratory, to demonstrate the impact of research.
- writing a letter.
- presenting testimony.
- distributing a press release about your research.
- presenting an educational session about the impact of eye disease.

There are many ways to amplify your message within your home country/region's vision research community, the international research community, collaborating organizations, and the press and public. Your choice of routes will be affected by the manpower and funding resources you have.

- **Copy communications with key government officials/ministries**
  Whether you write an informal personal letter or provide formal testimony, as appropriate, copy other key government contacts and their staffs. This both informs them of a vision issue that may affect their programs and makes them aware of a concerned and vocal constituency.
- **Copy communications to fellow researchers**
  To expand support and demonstrate the power of advocacy, share your communications with government officials with fellow researchers, and urge them to voice their own concerns.
- **Copy communications to existing and potential coalition partners and collaborating organizations**
  This informs partners of your actions and helps identify opportunities for joint advocacy.
- **Document activities in newsletters**
  If appropriate, contribute articles about your activities to your academic institution's newsletter or that of an advocacy organization or collaborating organization
- **Develop or participate in an electronic network of home-country researchers**
  Participants can stay abreast of each other's advocacy efforts, share information to use in message development or provide specific examples of advocacy communications.

- **Develop/engage in an electronic network with international researchers**
  Share useful information and compare advocacy approaches.
- **Develop a dedicated home-country Web site on the value of vision research**
  Build awareness by posting advocacy positions, key messages and fact sheets detailing the value of vision research being conducted within the home country/specific regions, and encourage visitors to support vision research funding.
- **Conduct public education and advocacy events**
  These can range from an academic institution-sponsored event to discuss recent research results to an advocacy event geared toward educating and influencing government officials. As noted in the When? Section, these can be timed to correlate with the government's budget decision-making process.
- **Conduct press outreach**
  Press relations can include visits to editorial boards, submitting letters to newspaper editors, issuing press releases and inviting press to attend events or tour your laboratory. Communications with the press should be in lay terms. Advocates need to be thoroughly prepared with their messages, anticipating and being able to respond to press questions. The examples below describe ways to use press releases.

Announce recent vision research results

Example: Appendix J
In a June 29, 2007, press release, NAEVR announced that it had submitted to Congress the results of an NEI-funded study which demonstrated the protective effect omega-3 polyunsaturated fatty acids against retinopathy in mice as an example of breakthrough NEI research that supports increased funding.

Announce communications submitted to government officials

Example: Appendix K
In a March 26, 2008, press release, NAEVR announced that it had submitted testimony to the U.S. House of Representatives supporting increased NIH/NEI funding. In this release, NAEVR identified the recent NEI research results it cited as examples of why NEI funding should be increased.

Announce the publication of reports

Example: Appendix L
In a September 12, 2007, press release, NAEVR reported that US census data for 2006 found that one in four individuals age 65-74 was still working, compared with one in five in 2000. NAEVR related that to the need for NEI funding. The press release also announced the publicatiion of *The Silver Book: Vision Loss,* a compendium of data on aging eye disease that NAEVR developed with the Alliance for Aging Research.

Announce release of a fact sheet

Example: Appendix M
In late September 2007, NAEVR distributed to the press a summary of the September 25 advocacy event on Capitol Hill in which it released *The Silver Book: Vision Loss* with the Alliance for Aging Research. This event was held on AMD Awareness Week (see When? Section) and was co-sponsored by AMD Alliance International, Prevent Blindness America and the Congressional Vision Caucus. (Note: The US Congress (especially the House of Representatives) has formed caucuses to draw attention to specific causes, ranging from ethnic and gender issues to specific diseases. Although these caucuses do not have legislative authority, NAEVR/AEVR often seeks caucus support to get greater attention from Congressional offices).

Announce an educational or advocacy event

Example: Appendix N
In late February 2008, NAEVR distributed to the press a summary of a February 26 educational event held on Capitol Hill entitled *Visual Imaging: Revolutionizing the Diagnosis and Treatment of Eye Disease.* Note that this was held in conjunction with numerous coalition partners, including organizations that represent imaging professionals.

Announce advocacy success

Example: Appendix O
In a February 14, 2008, press release, NAEVR announced that the major U.S. Veterans Services Organizations (VSOs) had joined NAEVR in requesting that the US Congress fund defense-related vision research.

How? Advocacy in action

This section distills information from all of the previous sections to present the mechanics of requesting and conducting an advocacy visit with a public or private official, as well as the appropriate follow-up.

A. Set an achievable goal

It is easy to get caught up in expectations. Determine what you want to accomplish and identify the resources you have to initiate and follow up on your action. Before even requesting a visit with a key policymaker, consider these questions.

- **Are introducing an issue, or are you following up on previous discussions?** Since it generally takes at least one meeting to establish the request and the underlying messages, it might be unrealistic to expect success on the first visit.

- **What is the context of your visit?** For example, will you request vision funding on behalf of yourself, your academic institution or the entire vision research community in your home country?
- **Are you committed to following through?** This means responding to questions, contacting other individuals recommended at the meeting, serving as a resource for vision-related questions and committing to regular communications with that office to keep it aware of your issue.

B. Requesting an advocacy visit

To ensure that your visit is as successful as possible, be fully prepared before making the request.

- **Who is the official, and why are they important?** This gives context to your visit, determining the advocacy messages you use and if the individual has direct decision-making authority (primary or secondary advocacy target).
- **What is the best way to communicate with this individual?** Evaluate whether it is directly with the individual or an assistant and the appropriate means to communicate (verbal, written or electronic, or any combination of these). As noted in the "What" section, consider how you target your message, that is, a personal story or formal argument approach or a combination.
- **Clearly state who you are representing,** whether yourself, your academic institution or the vision research community. As appropriate, note any special role you may play at the institution (for example, department chairperson) or with an advocacy organization.
- **How can you heighten interest in your visit?** Refer to past meetings or communications or the past support the target has shown; affiliation with your academic institution; mutual acquaintances; demonstrated interest in this issue; and/or personal experience with eye disease.
- **State the purpose of the visit and what you are requesting.** It is important to follow through with the intended reason for your visit and the accompanying request, even if other opportunities are presented onsite at the meeting (see below).
- **Use appropriate advocacy messages to support your request.** For example, if you are requesting increased vision research funding, provide a succinct paragraph of supporting data on the incidence and economic burden of eye disease (as appropriate, attach a fact sheet or other supporting data). It is also important to emphasize what will happen if your funding request is not successful (for example, more cases of blindness, fewer research grants, loss of young investigators).
- **Anticipate questions and challenges to your request.** Most often, policymakers will want to know more about an issue, especially how it affects their issue area. In tight budget times, they may want to discuss options to your funding request or know what will be the consequences of not taking action.

Example: Appendix P
On March 26, 2008, NAEVR Board President Dr. Stephen Ryan wrote to US Senator Tom Harkin (D-IA) requesting a visit, acknowledging his recent efforts to support medical research and reiterating reasons for an NEI funding increase.

Example: Appendix Q
On July 12, 2007, NAEVR Board President wrote to a staff member of the US House of Representatives Speaker Nancy Pelosi (D-CA) expressing appreciation for the visit, reiterating NAEVR's funding request, and offering to keep the office apprised of NEI research into eye disease prevention, a key issue for the Speaker.

C. Conducting the visit

No matter how much you prepare for an advocacy visit, each is unique, depending on the individual with whom you meet, how busy they are and how receptive they are to your message. You can control some variables, however, including being on time, being fully prepared with your message and ready to take advantage of all opportunities to discuss your issue and appropriate follow-up actions to your request.

- **Bring business cards and appropriate supporting materials,** such as your academic institution's newsletter, press release about your research or fact sheets that support your message.
- **Reinforce any personal connections, affiliations or acquaintances,** especially those that enhance support for your request.
- **Stay on message,** ensuring that you follow through with the stated purpose of your visit and associated request. Even if the recipient gets into other issues, bring the conversation back to your issue and specific request.
- **Determine next steps before the meeting ends,** which could range from requesting a follow-up meeting to learning about other individuals with whom you may need to communicate your request.
- **Reiterate your request at meeting's end** and repeat your plans for follow-up. Obtain business cards from the individual or assistant that will help in follow-up and identify the best way to communicate with this office (verbal, written, electronic).

D. Following up on the visit

Post-meeting communication with the recipient of your advocacy message is important, enabling you to reiterate your request and to put it in a context that may be elicit even greater responsiveness.

- **Prepare a follow-up communication,** reiterating your request and adding any advocacy messages that build upon your meeting's discussions. Describe additional follow-up plans.

- **As appropriate, share your communication with your academic institution or advocacy colleagues** to amplify your message.

E. Following up on formal communication with a policymaker

There are other communications that are shared with policymakers, including verbal and written testimony, fact sheets and summaries of educational or advocacy events that you or an organization may conduct. These can be sent to the appropriate legislators or policymakers with a cover letter that clearly states the funding request and how the attachment supports that request.

Conclusion

ARVO and NAEVR encourage all members of the vision research community to serve as advocates for vision research. In that regard, NAEVR will work with the ARVO Advocacy Committee and its International Advocacy Working Group to follow up on this document with additional resources.

About the National Alliance for Eye and Vision Research (NAEVR)

NAEVR is a US nonprofit coalition comprised of 55 professional, consumer and industry organizations involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education for eye and vision research sponsored by the National Institutes of Health (NIH), the National Eye Institute (NEI) and other federal research entities. Per the US Internal Revenue Service, NAEVR is a 501c4 "social welfare" organization, meaning that it can conduct unlimited advocacy on behalf of vision research. NAEVR has an affiliate organization.

Appendices

Appendix A

The Association for Research in Vision and Ophthalmology
Suite 250 • 12300 Twinbrook Parkway • Rockville, MD 20852-1606
240-221-2900 • Fax 240-221-0370 • www.arvo.org

ARVO WRITTEN TESTIMONY IN SUPPORT OF INCREASED FISCAL YEAR 2009 FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL EYE INSTITUTE (NEI)

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES SUBCOMMITTEE OF THE U.S. SENATE COMMITTEE ON APPROPRIATIONS

April 23, 2008

ABOUT ARVO

ARVO, the world's largest association of physicians and scientists who study diseases and disorders affecting vision and the eye, has more than 12,300 members from the United States and 73 countries. As some 80 percent of the 7,000 United States members have or are affiliated with NIH grants, ARVO submits these comments supporting increased FY2009 NIH and NEI funding.

ARVO REQUESTS FY2009 NIH FUNDING AT $31 BILLION, OR A 6.6 PERCENT INCREASE OVER FY2008, TO MATCH INFLATION/RESTORE PURCHASING POWER AND FUND YOUNG INVESTIGATORS/CLINICIAN SCIENTISTS

NIH is a world-leading institution and must be adequately funded so that its research can reduce healthcare costs, increase productivity, improve quality of life, and ensure our nation's global competitiveness. Although ARVO commends the Congressional leadership's actions to significantly increase NIH funding above the Administration's budget request in FY2008 appropriations, the net 0.46 percent increase meant a net loss in NIH purchasing power. For five consecutive years, NIH funding has failed to keep pace with the biomedical inflation rate and NIH has lost more than 10 percent of its purchasing power. The Administration's FY2009 budget, which proposes to freeze the NIH budget at the FY2008 level, threatens to further hinder the momentum of discovery leading to treatments that are saving lives—as well as restoring the quality of life—and maintaining the nation's competitive edge in medical research.

Adequate NIH funding is also essential to a strong and vibrant research community, which risks losing established investigators and failing to attract young scientists. The NIH funding situation threatens to affect an entire generation of young researchers. As noted in the March 2008 report entitled *A Broken Pipeline? Flat Funding of the NIH Puts a Generation of Science at Risk* and in March 13, 2008, House LHHS Appropriations Subcommittee Citizen Witness hearing testimony presented by the Federation of American Societies for Experimental Biology (FASEB), the 60,000 postdoctoral researchers who represent America's scientific future and are on the path to a lifelong career in research are being negatively affected by the decline in NIH's budget. This impact includes:

- Fewer hires, lower salaries, and increased layoffs in the research community
- Young scientists seeing their mentors struggle to maintain grant funding
- Students seeking job opportunities outside of research or in other countries

- An appreciable drop in applications in 2007 from 2006—by nearly 600—of R01 grant applications by previously unfunded researchers ("new investigators")
- An increase in the average age from 34.2 to 41.7 years for investigators who receive their first research project grant award

These concerns are especially acute for the eye and vision research community, especially for its clinician scientists, who have been so instrumental to the NEI's impressive track record of the translation of basic research into clinical applications that directly benefit patient care.

ARVO REQUESTS FY2009 NEI FUNDING AT $711 MILLION, OR A 6.6 PERCENT INCREASE OVER FY2008, TO ENSURE ALL AMERICANS' VISION HEALTH

The NEI was flat funded in FY2008, meaning that over the past five funding cycles it has lost 18 percent of its purchasing power, reducing the number of grants by 160, which threatens its impressive record of breakthroughs in basic and clinical research that have resulted in treatments and therapies to save and restore vision, as well as to prevent eye disease. Vision impairment/eye disease is a growing, major public health problem that disproportionately affects the aging and minority populations, costing the United States $68 billion annually in direct and societal costs, let alone reduced independence and quality of life. Adequately funding the NEI is a cost-effective investment in our nation's health, as it can delay, save, and prevent expenditures.

FY2009 NEI FUNDING AT $711 MILLION ENABLES IT TO LEAD COLLABORATIVE RESEARCH REFLECTING THE NEW PARADIGM OF 21st CENTURY HEALTHCARE THAT IS PREDICTIVE, PREEMPTIVE, PERSONAZLIED, AND PARTICIPATORY

NEI research addresses the NIH's overall major health challenges as set forth by NIH Director Elias Zerhouni, M.D.: an aging population; health disparities; the shift from acute to chronic diseases; and the co-morbid conditions associated with chronic diseases (e.g., diabetic retinopathy as a result of the epidemic of diabetes). NEI research responds to Dr. Zerhouni's vision for NIH research that is collaborative and cost-effective and meets the 21st century "P4Medicine" paradigm of predictive, preemptive, personalized, and participatory research and clinical practice. For example:

- One-quarter of all genes identified to date through NEI's collaboration with the Human Genome Project is associated with eye disease, such as age-related macular degeneration (AMD), retinitis pigmentosa (RP), and glaucoma. NEI-funded researchers have discovered gene variants strongly associated with an individual's risk of developing AMD, the leading cause of blindness in older Americans. These variants, responsible for about 60 percent of the cases of AMD, are associated with the body's inflammatory response and may relate to other inflammation-associated diseases, such as Alzheimer's and Parkinson's.

- NEI is currently conducting the second phase of its Age-Related Eye Disease Study (AREDS), which follows up on initial findings that high levels of dietary zinc and antioxidant vitamins (Vitamins C, E and beta-carotene) are effective in reducing vision loss in people at high risk for developing advanced AMD—by a magnitude of 25 percent. NEI estimates that 1.3 million Americans would develop advanced AMD if no treatment was given, and if all individuals at risk engaged in the AREDS supplement regimen,

more than 300,000 of them would avoid advanced AMD and any associated vision loss during the next five years.

- NEI's collaborative research into factors that promote or inhibit new blood vessel growth has resulted in the first generation of ophthalmic drugs approved by the Food and Drug Administration (FDA) to inhibit abnormal blood vessel growth in "wet" AMD, thereby stabilizing and restoring vision, and NEI's Diabetic Retinopathy Clinical Research (DRCR) Network is further evaluating these drugs for treatment of macular edema associated with diabetic retinopathy (DR).

These examples primarily reflect NEI's trans-Institute research within NIH. The NEI has also collaborated with other Department of Health and Human Services (DHHS) agencies, specifically to share the results of its basic and clinical research which may impact the product approval and reimbursement processes. For example:

- In a March 2008 meeting, NEI collaborated with FDA's drug and device Centers to consider the appropriateness of new clinical endpoints in glaucoma clinical trials. Advances in visual imaging technologies—many of which emerged from collaborative research between the NEI and the National Institute of Biomedical Imaging and Bioengineering (NIBIB)—have enabled researchers to better detect structural changes in the nerve fiber layer of the retina and contours of the optic nerve head. These structural changes could potentially be used as a direct endpoint in a clinical trial, rather than a surrogate endpoint such as elevated intra-ocular pressure, when appropriately correlated to functional changes in vision to assure clinical significance of a new therapy. This meeting, which followed a November 2006 joint NEI-FDA meeting on clinical endpoints in AMD and DR clinical trials, represents the cost–effectiveness of NEI funding, as its research results may ultimately shorten the time and cost associated with clinical trials and facilitate approval of new diagnostics/therapies.

- In collaboration with the Centers for Medicare and Medicaid Services (CMS), NEI has launched the *Comparison of AMD Treatments Trial* (CATT), a comparative effectiveness study of the two drugs used to block growth of abnormal blood vessels in patients with the "wet" form of AMD. NEI's collaboration with CMS could guide clinical practice and reduce costs to the Medicare program.

THE NEI'S DIMINISHED PURCHASING POWER JEOPARDIZES ITS ABILITY TO FOLLOW UP ON RESEARCH BREAKTHROUGHS FROM PAST INVESTMENT

Congress must adequately fund NEI so it can initiate promising new research, pursue results that have emerged from previous breakthroughs, and offer up its "fair share" of funding in its extensive collaborations. The number of NEI grants has declined by 160 over the past five years, from 1,214 in FY2004 to 1,054 in FY2008, representing myriad "lost opportunities"—any one of which could have been the key to curing eye disease or restoring vision. Examples of such lost opportunities include:

- Ocular gene therapy holds great promise for retinal degenerative diseases, in which nearly 200 gene defects have been implicated. Investigators supported by NEI and private-funding organization Foundation Fighting Blindness (FFB) have begun human clinical trials of a gene therapy to treat Leber Congenital Amaurosis (LCA), a rapid retinal degeneration that blinds infants in the first year of life. Previous research has restored

vision in dogs with LCA, and the results of the human clinical trials are forthcoming. Although the NEI could expand this program to target more diseases, current budget realities limit further research.

- Promising protocols proposed within the Diabetic Retinopathy Clinical Research Network will not be funded. The DRCR Network is a large, multi-center study that engages ophthalmologists and optometrists, many in community health centers, in basic and clinical research. Past NEI diabetes networks developed laser treatments for DR that save $1.6 billion annually in federal disability payments.

- NEI funding for epidemiological studies is already limited, which jeopardizes future research into the basis/progression of eye disease in additional ethic populations, such as Asian and Native Americans. Past NEI studies identified a three-fold greater risk of glaucoma in African Americans and glaucoma as the leading cause of irreversible vision loss in African Americans and Hispanics.

- NEI will not be able to fund proposed new Clinical Research Networks for AMD and for neuro-ophthalmic disorders. The latter could assist in understanding visual disorders associated with Traumatic Brain Injuries (TBI), especially those currently being incurred in record numbers by soldiers in Iraq and Afghanistan.

NEI research into other significant eye disease programs such as cataract will be threatened, along with quality of life research programs into low vision and chronic dry eye. This occurs at a time when the US Census cites significant demographic trends that will increase the public health problem of vision impairment and eye disease, such as the first wave of 78 million Baby Boomers celebrating their 65th birthday in 2010, with about 10,000 Americans turning 65 each day for 18 years afterward.

EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM INCREASING HEALTH COSTS, REDUCING PRODUCTIVITY, AND DIMINISHING QUALITY OF LIFE

The 2000 US Census reported that more than 119 million people in the United States were age 40 or older—the population most at risk for an age-related eye disease. The NEI estimates that more than 38 million Americans age 40 and older currently experience blindness, low vision or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. Although the current annual cost of vision impairment and eye disease to the US is $68 billion, it does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. This presents a major public health problem and financial challenge to the public and private sectors.

In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. As recently as March 2008, the NEI's *Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease* reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a "10" on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life. As a result, federal funding for the NEI is a vital and cost-effective investment in the health, and vision health, of our nation as the treatments and therapies emerging from research can preserve and restore vision.

ARVO urges FY2009 NIH and NEI funding at $31 billion and $711 million, respectively.

Appendix B

NAEVR
National Alliance For
Eye And Vision Research
Serving as Friends of the National Eye Institute

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PRESS RELEASE

FOR IMMEDIATE RELEASE
January 25, 2008

Contact: James F. Jorkasky
Executive Director
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NAEVR REQUESTS THAT EYE AND VISION RESEARCH REMAIN ELIGIBLE FOR FUNDING WITHIN THE FY2009 DOD PEER REVIEWED MEDICAL RESEARCH PROGRAM

(Washington, D.C.) Today, the National Alliance for Eye and Vision Research (NAEVR) requested that "eye and vision research" remain eligible for funding within the Fiscal Year (FY) 2009 Department of Defense (DOD) Peer Reviewed Medical Research Program (PRMRP). NAEVR released its request during an advocacy day it held for the Association for Research in Vision and Ophthalmology (ARVO), a NAEVR founding member. The twenty participating ARVO members sought support generally in all 50 Capitol Hill offices visited, while NAEVR Executive Director James Jorkasky joined participants in key districts and states to ask their Members of the House and Senate Defense Appropriations Subcommittee to serve as "champions."

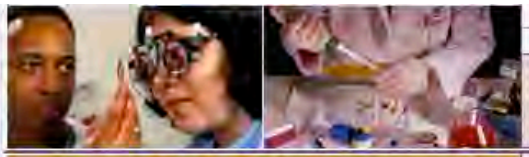
"The combat-related eye injuries being incurred in Iraq and Afghanistan are of an unprecedented, devastating nature," said Jorkasky, citing DOD statistics as well as a series of front-page articles from *USA Today* that have chronicled the challenges faced by newly sight-impaired soldiers. DOD reports that 16 percent of wartime injuries affect the eye—with optic nerve trauma the most grave—and that visual disorders occur in 80 percent of the cases associated with Traumatic Brain Injury (TBI), such as double vision, light sensitivity, and inability to read print. "These injuries have both acute and chronic implications for an individual's vision health and productivity through the remainder of their military service and into their civilian lives."

Eye and vision research has been listed in FY2006-FY2008 for this program, which enables researchers in eligible areas to compete for a pool of $50 million of peer-reviewed funding. In FY2006, its first year of eligibility, the vision community submitted 52 grant requests to the DOD, or 8 percent of all submissions, and was awarded 6 grants out of the 51 issued, for a funding total of $5.4 million, or 12 percent. Examples of this research include: corneal healing, as well as ways to improve corneal transplantation by regulating the lymphatic pathway servicing the cornea; corneal wound infection control; laser injuries; and support for ongoing work on a "Retinal Implant" to restore vision through electronic stimulation of the retina.

Although vision research was listed in FY2007, the PRMRP was not funded in the FY2007 Joint Funding Resolution. Currently, vision community researchers are eagerly

awaiting the DOD's program announcement requesting FY2008 grant submissions, which will be posted on the PRMRP site at:
http://cdmrp.army.mil/pubs/press/2008/08prmrppreann.htm

The National Alliance for Eye and Vision Research (NAEVR) is a non-profit advocacy coalition comprised of 55 professional, consumer, and industry organizations involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education for eye and vision research sponsored by the National Institutes of Health (NIH), the National Eye Institute (NEI) and other federal research entities. Visit NAEVR's Web site at www.eyeresearch.org.



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SPEAK UP for Eye and Vision Research
Tell Congress to Fully Fund the National Eye Institute

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NAEVR

NAEVR in Action

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- Eye Fact Center
- Press Center
- Newsletters
- Spread the Word
- Tell Your Story
- Link to Our Site
- Resources and Links
- Privacy Policy
- Site Map

NEI and FDA Collaborate to Address Clinical Trial Issues for Glaucoma Drug and Device Diagnostics and Therapies

Program Co-Chairs Robert N. Weinreb, M.D. (left) and Paul Kaufman, M.D. (right) with NEI Director Paul Sieving, M.D., Ph.D.

On March 13-14, 2008, the National Eye Institute (NEI) within the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) held a *Glaucoma Clinical Drug Trial Design and Endpoints Symposium*. This collaborative meeting, which involved both the drug and device approval divisions within the FDA—specifically the Center for Drug Evaluation and Research (CDER) and the Center for Devices and Radiological Health (CDRH)—engaged glaucoma investigators and clinicians in a discussion of how results from research studies can apply to clinical trials used to support the approval of new drug and device diagnostics and therapies for glaucoma.

Anne Coleman, M.D. (University of California-Los Angeles), who addressed quality of life indicators, with NEI co-sponsor Rick Ferris, M.D.

"This was a landmark meeting, and the glaucoma community made considerable progress. We learned from NEI how to improve clinical trial design, and heard a great deal of flexibility from the FDA's drug and device staff regarding new outcomes endpoints that may be used to support approvals of the next generation of diagnostic and therapeutic products," said Robert N. Weinreb, M.D. (Hamilton Glaucoma Center/University of California-San Diego), who served as Program Co-Chair with Paul Kaufman, M.D. (University of Wisconsin at Madison). Dr. Kaufman added that, "This was an excellent opportunity for investigators to understand from FDA what is involved in the testing of new drugs on new sites within the eye and in ways we have never treated before. We now know the approval process can be faster than was thought possible due to FDA's receptivity to new endpoints for clinical trials. This will enable researchers to 'telescope' clinical trials based on these new guidelines and potentially reduce the cost and time of getting new therapies to patients."

FDA co-sponsors Malvina Eydelman, M.D. (Center for Devices and Radiological Health) and Wiley Chambers, M.D. (Center for Drug

Glaucoma, the second leading cause of preventable vision loss in the United States, is a complex set of neurodegenerative diseases that damages the optic nerve and leads to loss of visual function. If untreated, it can lead to blindness. An estimated 2.2 million Americans have the disease, and an additional two million do not know they have it, as it often has no symptoms until substantial vision loss occurs. Every American over the age of 60 is at risk, and certain minority populations are at especially high risk, with African Americans having a three times greater risk of developing the

disease than white Americans. Glaucoma is the leading cause of irreversible vision loss in African Americans and Hispanics.

Evaluation and Research)

Even though elevated intra-ocular pressure (IOP) does not necessarily mean that a person has glaucoma, the current FDA-approved drug and device therapies have focused on reducing IOP since there is consensus in the medical community that lowering pressure inside the eye can, in many cases, slow glaucoma damage or vision loss. This was demonstrated in several NEI-funded studies, including the Early Manifest Glaucoma Trial (EGMT), which demonstrated that IOP reducing drugs slowed progression of the disease, and the Ocular Hypertension Treatment Study (OHTS), which demonstrated that IOP reducing drugs delayed the onset of glaucoma in people at high risk. The OHTS study also identified anatomical risk factors, including changes in the optic nerve and thinness of the cornea, which may be predictive of the disease.

Murray Fingeret, O.D. (VA NY Health System), a panel discussant, Scott Christensen (The Glaucoma Foundation) and speaker Christopher Girkin, M.D. (University of Alabama at Birmingham). Dr. Girkin serves as a lead investigator in the NEI-funded African Americans With Glaucoma Study.

Advances in visual imaging technologies have enabled researchers to better detect structural changes in the nerve fiber layer of the retina and the contours of the optic nerve head. To be used as outcomes variables in clinical trials submitted to the FDA, these structural changes must be demonstrated to have a high correlation with functional changes in vision to assure the clinical significance of a new therapy.

As researchers noted, glaucoma is a complex disease in which detectable structural and functional changes may not progress linearly or in concert, that is, early disease may be detected and characterized primarily by observable structural change, middle stage by both, and end stage primarily by measurable functional change. As a result, the regulatory process should be flexible to reflect this disparity between detectable structural and functional changes especially when considering, for example, a new class of neuro-protective drugs that could mitigate damage to the optic nerve before it is manifested in visual function change. Much of the meeting's discussion focused on how these new structural endpoints—which would be a direct endpoint, rather than a surrogate endpoint such as IOP—are incorporated into clinical trials and, as appropriate, correlated to visual function and concomitant quality of life indicators to ensure clinical significance and ultimate benefit to patients.

Rohit Varma, M.D. (Doheny Eye Institute/University of Southern California) presented findings from NEI's Los Angeles Latino Eye Study (LALES), in which glaucoma w as undetected and untreated in 75 percent of those diagnosed with the disease

"The development of an exciting new generation of treatments for glaucoma will require close collaboration between researchers and the FDA if we are to be able to demonstrate that the treatments are safe and effective in the shortest time possible," said NEI Clinical Director Rick Ferris, M.D. He was joined by symposium co-sponsors Wiley Chambers, M.D. (CDER/Acting Director, Division of Anti-Infective and Ophthalmic Products) and Malvina Eydelman, M.D. (CDRH/Director, Division of Ophthalmic and ENT Devices) in predicting a new generation of glaucoma drugs and devices, including combinations of those

Left to right: David Greenfield, M.D. (Bascom Palmer Eye Institute/University of Miami), Jack Cioffi, M.D. (Devers Eye Institute) and Jeffrey Liebmann, M.D. (Manhattan Eye, Ear, and Throat Hospital) addressed aspects of structural and

products that deliver drug therapies directly into the eye.

functional changes in glaucoma

12300 Twinbrook Parkway, Suite 250, Rockville, MD 20852 TEL 240-221-2900 FAX 240-221-0370

Masthead photography courtesy of the National Eye Institute

Appendix D

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NAEVR SUPPORTS A 6.6% FUNDING INCREASE FOR THE NIH/NEI IN FY2009

The National Alliance for Eye and Vision Research (NAEVR), on behalf of the eye and vision research community, requests that in Fiscal Year (FY) 2009 Congress fund the National Eye Institute (NEI) at $711 million and the National Institutes of Health (NIH) at $31 billion, reflecting a 6.6% increase over FY2008 funding.

The 6.6% increase represents the current biomedical inflation rate of 3.6%, plus a 3% increase to begin to restore the NIH/NEI purchasing power, which has been eroded by almost 18% over the past five funding cycles. This increase is necessary to maintain the momentum of discovery that will prevent the onset of eye disease and restore vision, as well as to preclude "missed opportunities" to build upon the past investment at the NIH.

Vision impairment and eye disease is a major public health problem that is growing and which disproportionately affects the aging and minority populations.

Today, more than 38 million Americans age 40 and older experience significant vision impairment and eye disease. This includes 3.3 million who are blind or experience low vision, and this number is expected to grow to 5.5 million by 2020. About 35 million Americans experience an age-related eye disease, including age-related macular degeneration (AMD, the leading cause of vision loss in older Americans), glaucoma, diabetic retinopathy, and cataracts, and this number will grow to 50 million by 2020.

Additionally, the Hispanic, African American, and Native American populations experience a disproportionate incidence of glaucoma, cataracts and diabetic retinopathy, the latter being the leading cause of blindness in individuals of all races in the age group of 25-74 years.

The economic and societal costs of vision impairment and eye disease are significant and growing. Adequately funding NEI is a cost-effective investment in our nation's vision health.

Current annual federal funding for the NEI is less than one percent of the $68 billion spent annually on visual disorders and disabilities—which does not even fully quantify the impact of lost productivity, reduced independence, and diminished quality of life. Adequately funding the NEI can delay, save, and prevent expenditures, especially those to the Medicare and Medicaid programs. For example:

- NEI-funded researchers have developed treatments for diabetic retinopathy that save $1.6 billion annually in disability payments.

Appendix D

- NIH Director Dr. Elias Zerhouni heralded as an NIH breakthrough NEI's discovery of an AMD gene. With adequate funding, the NEI can develop appropriate diagnostics for early detection, as well as promising therapeutic strategies for the 10 million Americans that experience AMD and whose healthcare costs are primarily covered by Medicare.

Past NEI-funded basic and translational research is resulting in treatments to slow the progression of vision loss and restore vision.

The past federal investment in the NEI is paying off in terms of new treatments and therapies for visual disorders affecting Americans of all ages and races. For example:

- NEI is conducting additional clinical trials on nutritional supplements that may slow the progression of AMD, following previous research demonstrating that zinc and three antioxidant vitamins (Vitamins C, E and beta-carotene) are effective in reducing vision loss in people at high risk for developing advanced AMD.

- An NEI-sponsored study has found that eye injections of bone-marrow derived stem cells prevented vision loss in two rodent models of Retinitis Pigmentosa (RP), a family of eye diseases that cause vision loss. This study raises the possibility that patients could receive an injection of their own bone marrow stem cells to preserve central vision.

- NEI-funded researchers reported a protective effect from omega-3 fatty acids against retinal disease in mice. This may have a significant impact on research into retinal disease in humans, including AMD, diabetic retinopathy, and Retinopathy of Prematurity in premature infants.

- NEI-supported investigators have begun human clinical trials of a gene therapy to treat neurodegenerative eye diseases, including Leber Congenital Amaurosis (LCA), which is a rapid retinal degeneration that blinds infants in the first year of life. Previous research has restored vision in dogs with LCA, and the results of the human clinical trials are expected later this year.

The eye and vision research community urges you to strongly support FY2009 NEI funding at $711 million and NIH funding at $31 billion. NEI-sponsored research, which results in therapies that reduce healthcare expenses and returns individuals to productive roles in society, is a cost-effective investment in maintaining the vision health of all Americans.

Eye and Vision Breakthroughs:
Keep The Research Drive Alive!
www.eyeresearch.org

Appendix D

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NAEVR SUPPORTS A 6.6% FUNDING INCREASE FOR THE NIH/NEI IN FY2009

- **The 6.6% funding increase represents the current biomedical inflation rate of 3.6%, plus a 3% increase to begin to restore the NIH/NEI purchasing power, which has been eroded by almost 18% over the past 5 funding cycles.**

- **The 6.6% increase would result in NEI funding of $711 million, an approximate $44 million increase over FY2008; the 6.6% increase would result in NIH funding of $31 billion, $1.9 billion over the net program level of $29.2 billion in FY2008.**

- **Flat funding has precluded NEI's ability to follow up on past breakthroughs in vision research, which have been responsive to NIH Director Dr. Zerhouni's goal of a 21st century paradigm for research and clinical practice that is preemptive, predictive, personalized, and patient-focused.**

- **The amount and timing of appropriations is important, as a delay in the ability of NEI to provide grants jeopardizes the continuity of research (e.g., retaining trained personnel, having adequate supplies for experimentation).**

Eye Disease/Vision Impairment is a Major Public Health Problem

- Eye disease and vision impairment is a major public health problem growing exponentially due to an aging population, a disproportionate incidence in minority populations, and as a result of other chronic disease, such as diabetic eye disease.

- NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease, such as age-related macular degeneration (AMD, the leading cause of vision loss in older Americans), glaucoma, diabetic retinopathy, or cataracts. This number will grow to 50 million by year 2020.

- The $68 billion annual cost of vision impairment and eye disease does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality.

Adequately Funding NIH/NEI is Vital to Our Nation's Vision Health

- The FY2008 NEI budget of $667 million is less than one percent of the $68 billion annual cost of eye disease and vision impairment. The government spends about $1.20 per person, per year, to combat eye disease. Increasing FY2009 NEI funding by $44 million to $711 million means spending about an additional dollar for each of the 38 million sight-impaired Americans.

Appendix D

- The NEI is a leader in the translation of basic research into clinical practice, conducting more than 60 clinical trial networks since its founding in 1968. Networks to treat/prevent diabetic eye disease have resulted in treatments that are more than 90% effective and have saved the federal government more than $1.6 billion a year in disability costs.

- The NEI is a leader in trans-Institute research. It collaborated with the National Human Genome Project to discover gene variants associated with age-related macular degeneration (AMD), the leading cause of blindness that affects more than 10 million Americans. Without adequate funding, the NEI will not be able to develop diagnostics for early detection or promising therapies.

- The NEI's collaboration with the National Cancer Institute has resulted in the first generation of Food and Drug Administration (FDA)-approved ophthalmic drugs to inhibit abnormal blood vessel growth in the "wet" form of AMD, halting further vision loss and restoring vision. Without adequate funding, the NEI will not be able to conduct clinical trials on these promising therapies for diabetic eye disease.

- In 2006, the NEI began the second phase of its Age-related Eye Disease Study, which had previously demonstrated a 25 percent reduction in the progression to the advanced form of AMD due to nutritional supplements, including zinc and antioxidant vitamins. Without adequate funding, the NEI will not be able to expand this preventive research into a cost-effective means by which to inhibit disease progression.

- In 2007, NEI-funded researchers reported a protective effect from omega-3 fatty acids against retinal disease in mice. This finding may have a significant impact in further research into retinal disease in humans, including age-related macular degeneration (AMD), diabetic retinopathy, and Retinopathy of Prematurity in premature infants.

Flat Funding has Precluded NEI Follow-up on Previous Breakthroughs

- Total NEI grants declined from 1214 in FY2004 to 1054 in FY2008—a decline of 160.

- NEI's ability to follow up on the genetic basis of eye disease with diagnostics and treatments is severely limited. To date, one-quarter of all genes identified through the Human Genome Project have been associated with eye disease.

- Promising protocols proposed within the Diabetic Retinopathy Clinical Research (DRCR) Network will not be funded. The DRCR Network is a large, multi-center study that engages ophthalmologists and optometrists, many in community health centers, in basic and clinical research into diabetic eye disease.

- NEI will not be able to fund proposed new Clinical Research Networks for AMD and for Neuro-ophthalmic disorders. The latter could assist in understanding vision disorders associated with Traumatic Brain Injury (TBI), especially that currently experienced in record numbers by soldiers in Iraq and Afghanistan.

#17 in a series

Investment in research saves lives and money

Research!America
AN ALLIANCE FOR DISCOVERIES IN HEALTH®

facts about:

Vision & Blindness

"If you think research is expensive, try disease."
— Mary Lasker 1901–1994

Today:

- 3.6 million Americans age 40 and older are blind or have impaired vision that cannot be corrected by eyewear. The most common causes are macular degeneration, glaucoma, cataract and diabetic retinopathy.*
- Americans age 80 and older are the fastest growing segment of our population and have the highest rate of blindness.**
- Latinos have higher rates of age-related visual impairment and blindness than other ethnic groups. Visual impairment often goes undetected in Latinos because of limited access to adequate eye care services.†
- 5 million Americans age 50 and older suffer from dry eye, which can cause pain, permanently damage the eye and reduce productivity.††

SOURCE: *PREVENT BLINDNESS AMERICA AND NATIONAL EYE INSTITUTE. VISION PROBLEMS IN THE U.S. 2008.
**THE EYE DISEASES PREVALENCE RESEARCH GROUP. ARCHIVES OF OPHTHALMOLOGY 2004, 122(4): 477-485.
†VARMA, R. ET AL. OPHTHALMOLOGY 2004, 111(6): 1132-1140.
††DRY EYE WORKSHOP REPORT (WWW.TEARFILM.ORG)

The Cost:

- Eye disease and vision loss cost the U.S. $68 billion annually.*
- The average annual salary for visually impaired adults is nearly $10,000 less than for those with normal vision. The visually impaired are also less likely to be employed—44% compared with 85% of adults with normal vision.**

SOURCE: *NATIONAL EYE INSTITUTE
**REIN, D.B. ET AL. ARCHIVES OF OPHTHALMOLOGY 2006, 124: 1754-1760.

survivor

NAME: HYMAN SHAPIRO
AGE: 81
DISEASE: MACULAR DEGENERATION

Hyman Shapiro of Rockville, Maryland, practiced law for 45 years until vision problems made it too difficult to read the law books. In 1988, he was diagnosed with age-related macular degeneration (AMD) and at the time was told there was no treatment.

Three years later, Hyman learned about the Age-Related Eye Disease Study (AREDS) sponsored by the National Eye Institute. He volunteered to be part of the study. AREDS successfully showed that high levels of antioxidants and zinc significantly reduce the risk of advanced AMD and help people keep their vision.

Since participating in AREDS, Hyman has kept up with the latest research, and today there are a number of methods to slow the progression of AMD. Hyman has had laser treatments to halt the leakage of blood vessels in his right eye, is undergoing photodynamic therapy and receives injections of the medicine ranibizumab, which blocks abnormal blood vessel growth and leakage in the retina.

"I try to be optimistic about the future of eye research. Someday the pall of blindness will be conquered and millions of people will be able to live useful, independent lives instead of needing leader dogs or caretakers."

Despite his visual impairment, Hyman keeps active, serving on the Montgomery County (Maryland) Property Review Board, which decides whether the state has offered just compensation for private land seized for public use. The self-described "baby" of that group, he emphasizes the importance of retirees serving their communities.

SAVING LIVES SAVING MONEY

HOW RESEARCH SAVES LIVES:

- Glaucoma is the leading cause of blindness in African Americans. Half of these glaucoma cases could be delayed or prevented with prescription eye drops.*
- Older drivers with cataracts are more likely to have automobile accidents. Cataract surgery cuts the number of crashes by these drivers in half.**

SOURCE: * HIGGINBOTHAM, E.J. ET AL. ARCHIVES OF OPHTHALMOLOGY 2004, 122(6): 813-820.
**OWSLEY, C. ET AL. JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 2002, 288(7): 841-849.

HOW RESEARCH SAVES MONEY:

- Everyone with diabetes is at risk for developing diabetic retinopathy. NIH-funded researchers have developed new treatments that delay or prevent diabetic retinopathy, saving the U.S. $1.6 billion a year.*
- A treatment to delay the progression of glaucoma could reduce the economic burden of the disease since the average annual cost to treat an early stage patient is $623 compared to $2,511 for a late-stage patient.**

SOURCE: *NATIONAL EYE INSTITUTE, NATIONAL INSTITUTES OF HEALTH (WWW.NEI.NIH.GOV)
**LEE, P.P. ET AL. ARCHIVES OF OPHTHALMOLOGY 2006, 124: 12-19.

facts about: Vision & Blindness

Hope for the Future:

- NEI-funded research suggests that increasing omega-3 fatty acids in the diet of premature infants could prevent or decrease severity of retinopathy of prematurity by protecting against abnormal blood vessel growth.*
- Breakthroughs in identifying gene variations in age-related macular degeneration could result in new screening tests and preventive therapies for the leading cause of blindness in older Americans.**

SOURCE: *CONNOR, K.M. ET AL. NATURE MEDICINE 2007; 13: 868-873
**NATIONAL EYE INSTITUTE

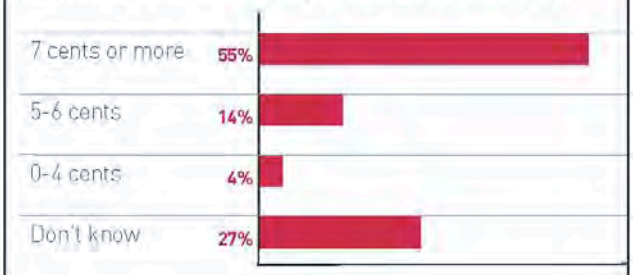
The Bottom Line:

More than 38 million Americans age 40 and older are blind, visually impaired or have an age-related eye disease, and the number is only expected to grow as the population ages. Increased investment in eye and vision research is needed now to help reduce the number of visually impaired Americans and the costs associated with treating and caring for them.*

SOURCE: *THE EYE DISEASES PREVALENCE RESEARCH GROUP. ARCHIVES OF OPHTHALMOLOGY 2004; 122(4)

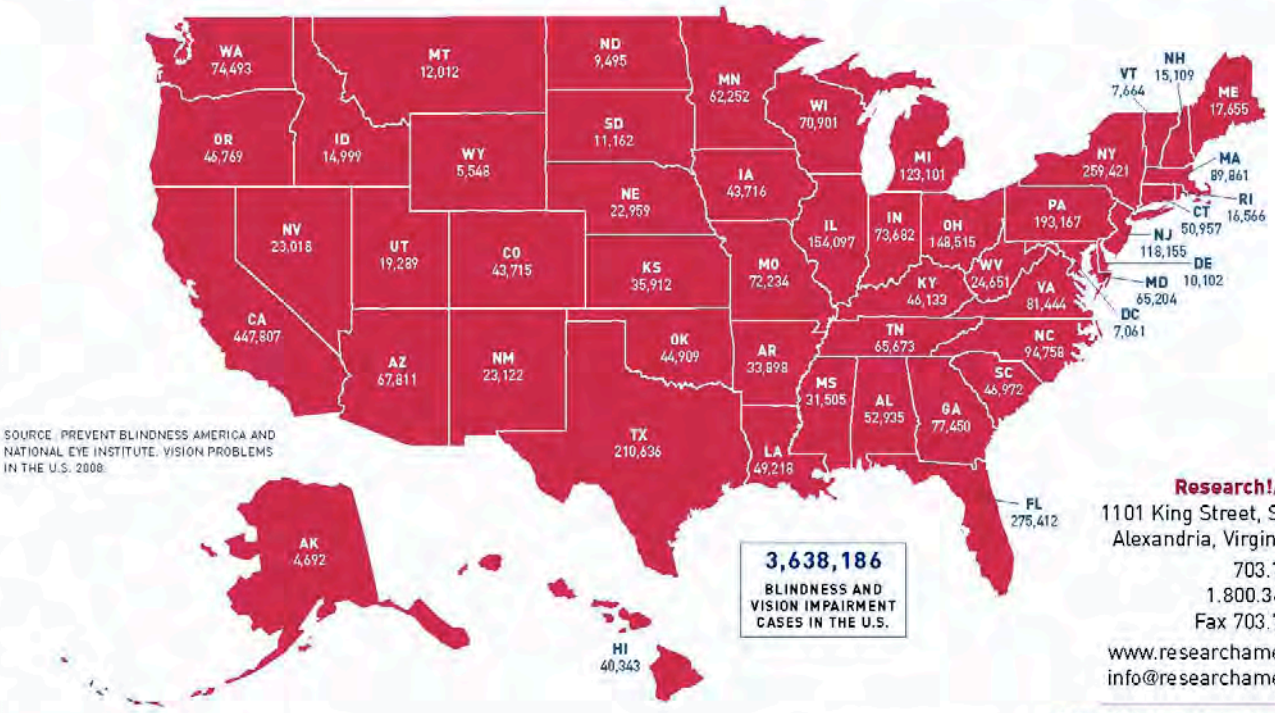
Americans Want More Spent on Medical and Health Research

Currently, about 6 cents of each health dollar spent in the U.S. is spent on medical and health research. How many cents of each health dollar do you think we SHOULD spend?



SOURCE: TRANSFORMING HEALTH POLL, 2007
CHARLTON RESEARCH COMPANY FOR RESEARCHAMERICA

Cases of blindness and vision impairment in Americans 40 and older



SOURCE: PREVENT BLINDNESS AMERICA AND NATIONAL EYE INSTITUTE. VISION PROBLEMS IN THE U.S. 2008

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703.739.2577
1.800.366.CURE
Fax 703.739.2372
www.researchamerica.org
info@researchamerica.org

For additional information, contact
National Alliance for Eye and Vision Research at 240.221.2905
OR www.eyeresearch.org

Lasker/Funding First is a founding partner in this series of fact sheets. *Lasker/Funding First* is the medical and health research policy program of the Mary Woodard Lasker Charitable Trust. **www.laskerfoundation.org**

17.2.408

FOR IMMEDIATE RELEASE

For more information:
Sarah Hecker
Prevent Blindness America
312-363-6035

THIRD ANNUAL "EYES ON CAPITOL HILL" EVENT PROVIDES PARTICIPANTS WITH OPPORTUNITY TO MEET WITH GOVERNMENT LEADERS

Prevent Blindness America Arranges Close to 150 Meetings with Congressional Offices for Vision Advocates

CHICAGO (Feb. 25, 2008) – Prevent Blindness America, the nation's leading volunteer eye health and safety organization, celebrated the success of the third annual "Eyes on Capitol Hill" campaign, held in Washington, DC. The program provides participants the opportunity to meet with their own state's legislators and share their personal experiences with vision loss. Through the event, vision advocates had nearly 150 appointments with Members of Congress and Congressional staff to educate important decision makers about the need for continued funding for research and programs to prevent vision loss.

"For the third consecutive year, advocates gave a voice to vision in congressional meetings," said Daniel D. Garrett, senior vice president of Prevent Blindness America. "Through their participation, our delegates were able to put a face on vision health issues and educate lawmakers on what more needs to be done in the fight to prevent blindness and vision loss."

After hundreds of applications were submitted, Prevent Blindness America selected more than 70 people to serve as delegates for the event. Adults and children who have had their vision impacted by either eye disease or eye injuries were sponsored by Prevent Blindness America to attend. All travel expenses were covered by the organization.

"We would like to thank all of our participants for allowing us to help them tell their stories," added Garrett. "We hope that through their experience with Eyes on Capitol Hill that they will be inspired to become vision care advocates in their own states."

In the United States today, one in 20 preschool children has a vision problem, and for adults, the estimated cost associated with adult vision diseases is $51.4 billion annually. As federal and state budget cuts continue to threaten public access to quality vision care services, Prevent Blindness America and its affiliates are helping to introduce bills across the country to help fund vision programs. Through events such as Eyes on Capitol Hill, the group hopes to raise the consciousness level of government leaders to the impact that vision health has on the economy and quality of life for Americans.

-More-

For more information on Eyes on Capitol Hill or on how you can contact your state representative to ask for their support on vision-related issues, call Prevent Blindness America at 1-800-331-2020 or visit www.preventblindness.org.

About Prevent Blindness America

Founded in 1908, Prevent Blindness America is the nation's leading volunteer eye health and safety organization dedicated to fighting blindness and saving sight. Focused on promoting a continuum of vision care, Prevent Blindness America touches the lives of millions of people each year through public and professional education, advocacy, community and patient service programs and research. These services are made possible through the generous support of the American public. Together with a network of affiliates, divisions and chapters, it's committed to eliminating preventable blindness in America. For more information, or to make a contribution to the sight-saving fund, call 1-800-331-2020 or visit us on the Web at www.preventblindness.org.

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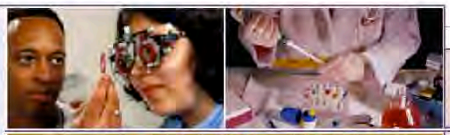

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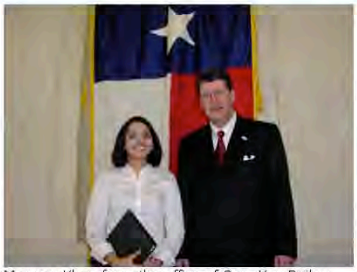
In January 25 Advocacy Day, ARVO Researchers Make FY2009 NIH/NEI and Defense-related Vision Research Funding Requests to Congress

Legislative Update
January 28, 2008

As in past years, the timing of the Association for Research in Vision and Ophthalmology's (ARVO) January Program Committee meeting enabled an Advocacy Day of 50 Congressional visits by the twenty participants early in the legislative session—one of the first conducted by any organization in the second session of the 110th Congress. Using just-released position papers and talking points developed by NAEVR, participants requested a Fiscal Year (FY) 2009 increase in National Institutes of Health (NIH) and National Eye Institute (NEI) funding of 6.6 percent, reflecting the biomedical inflation rate of 3.6 percent, plus 3 percent to begin restoring the nearly 18 percent purchasing power lost in the past five funding cycles. In addition to an increase in NEI funding—the Institute was flat-funded in FY2008 at $667.1 million—participants also emphasized the importance of the timeliness of appropriations, such that the continuity of research is not jeopardized by lay-offs of trained staff or lack of supplies for experimentation. The ARVO researchers also educated each office with position papers and talking points about the importance of defense-related vision research, urging each Member to write a letter of support to the House and Senate Defense Appropriations Subcommittee leadership for the continued eligibility of eye and vision research for the $50 million pool of peer-reviewed funding in the Department of Defense's Peer Reviewed Medical Research Program (PRMRP). NAEVR selected offices of potential Subcommittee "champions" for this continued listing and ensured that the ARVO constituent from that district or state made the request.

The FY2009 budget/appropriations process begins in earnest with the release of the President's budget request on February 4, at which time NEI will also release its FY2009 Congressional Justification. The House Labor, Health and Human Services, and Education (LHHS) Subcommittee plans to hold its NIH hearing on February 26/27—NAEVR will attend and report on the testimony from NIH Director Dr. Elias Zerhouni and Institute Directors. NAEVR has also submitted its request to testify at the Subcommittee's Public Witness hearings, likely to be held in late March/early April.

ARVO Advocacy Participants included (from left to right): Front Row: Carol Toris, Ph.D. (University of Nebraska Medical Center); Muna Naash, Ph.D. (University of Oklahoma Health Science Center); Janey Wiggs, M.D., Ph.D. (Harvard Medical School); Thomas Millar, Ph.D. (University of Western Sydney/Australia); Filippo Drago, M.D., Ph.D. (University of Catania/Italy); **Second Row**: Rajiv Mohan, Ph.D. (University of Missouri-Columbia); ARVO Executive Director Joanne Angle; Neeru Gupta, M.D., Ph.D. (University of Toronto/St. Michael's Hospital/Canada); Claude Burgoyne, M.D. (Devers Eye Institute); **Third Row:** Lenworth Johnson, M.D. (University of Missouri-Columbia); Erik van Kuijk, M.D., Ph.D (University of Texas Medical Branch /Galveston); Ron Adelman, M.D., Ph.D (Yale University School of Medicine); Debra Nickla, Ph.D. (New England College of Optometry); **Fourth Row:** Michael Kirby, Ph.D. (Loma Linda University); Michael Robinson, Ph.D. (Miami University); **Not Pictured:** Linda McLoon, Ph.D. (University of Minnesota); Todd Margolis, M.D., Ph.D (University of California-San Francisco); and Dong Chen, M.D., Ph.D (Schepens Eye Research Institute).



Maryam Khan from the office of Sen. Kay Bailey

Dr. Kirby, Dr. Margolis, and Dr. Millar (far right,

Hutchison (R-TX), an LHHS and Defense appropriator, met with Dr. van Kuijk. Ms. Khan had previously conducted vision research at Northwestern University.

one of three ARVO international members participating) met with Kristin Wikelius from the office of Sen. Dianne Feinstein (D-CA). The group also met with House Speaker Nancy Pelosi's (D-CA) staff in the U.S. Capitol.

Tim Steinemann, M.D., and Dr. Johnson (far right) met with Philip Young, a DOD Fellow in the office of Sen. Kit Bond (R-MO) and a former Special Operations soldier in Iraq. Dr. Johnson, a constituent and member of the National Advisory Eye Council (NAEC) and the NIH Council of Councils that manages the NIH common fund, requested that Defense appropriator Sen. Bond champion the continued listing of eye and vision research in DOD peer reviewed funding. Dr. Steinemann (Case Western Reserve University), who chairs the American Academy of Ophthalmology's (AAO) Research, Regulatory, and External Affairs Committee, joined in visits prior to the next day's AAO Federal Secretariat meeting.

Dr. McLoon with Ryan Crowley in the office of Sen. Amy Klobuchar (D-MN). Recently, Dr. McLoon hosted in her laboratory staff members from the offices of Sen. Norm Coleman (R-MN), a member of the Special Aging Committee, and Cong. Betty McCollum (D-MN), an LHHS appropriator.

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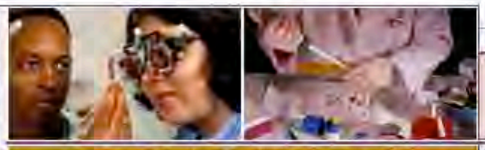
Masthead photography courtesy of the National Eye Institute



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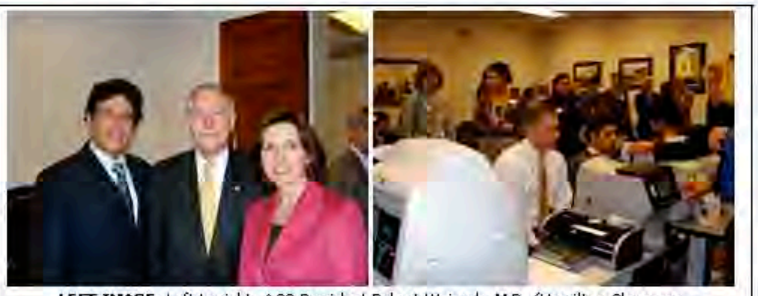
AGS Advocates for Glaucoma Awareness and Research in Capitol Hill Visits and a Glaucoma Screening Event on the First-ever World Glaucoma Day

On March 6, members of the American Glaucoma Society (AGS) visited nearly 100 Capitol Hill offices to educate Congress about the incidence of glaucoma and the need for increased vision research funding. This first-ever AGS Advocacy Day—held on the first-ever World Glaucoma Day—was accompanied by a luncheon screening that included real-time optic nerve and pressure evaluation of the eye. These events represented two of the more than 300 events being held globally to expand awareness of the disease, which can damage the optic nerve and lead to vision loss.



LEFT IMAGE: Left to right: AGS President Robert Weinreb, M.D. (Hamilton Glaucoma Center/University of California San Diego), Cong. Pete Sessions (R-TX), and Advocacy Day Program Co-Chair Anne Coleman, M.D. (Jules Stein Eye Institute/University of California Los Angeles);
RIGHT IMAGE: Foreground: Cong. Sessions participates in the screening

The AGS's glaucoma specialists and researchers focused on three important messages:

- Glaucoma awareness, as it is the second leading cause of preventable blindness in the United States and worldwide and needs to be diagnosed and treated as early as possible to mitigate vision loss. As a result, individuals at risk (especially in African American and Hispanic communities, in which it is the leading cause of irreversible vision loss) and those over the age of 40 should have regular, comprehensive eye exams that include careful examination of the optic nerve and measurement of eye pressure.
- Members of the House were encouraged to co-sponsor House Resolution 981, sponsored by Cong. Tammy Baldwin (D-WI) and Cong. Pete Sessions (R-TX) recognizing March 6 as the first-ever World Glaucoma Day.
- All members were urged to support a 6.6 percent increase in Fiscal Year (FY) 2009 funding for the National Institutes of Health (NIH) and the National Eye Institute (NEI), the latter of which was flat-funded in FY2008. The AGS utilized NAEVR's position paper and talking points in its visits.

"Although many of the AGS members had not previously visited Capitol Hill, they were articulate and effective advocates with a powerful message," said NAEVR Executive Director James Jorkasky who, with NAEVR Advocacy Manager David Epstein, accompanied the participants in meetings the entire day. "Members and their staffs were especially interested in how glaucoma is a 'sneak thief' of vision loss, often undetected until there is significant vision loss. That is why the accompanying screening event was so important in emphasizing the message about early diagnosis and treatment."

Cong. Pete Sessions, a sponsor of HR 981, provided a welcome. "We need to be concerned about vision loss around the world. Even though the United States is a leader in eye and vision research, we still have many challenges in getting individuals diagnosed and treated for blinding eye diseases." Cong. Gene Green (D-TX), a co-chair of the Congressional Vision Caucus, also attended the two-hour event, which drew a steady stream of staff.

NAEVR is posting all events related to World Glaucoma Day in a dedicated section of its Web site at www.eyeresearch.org

Dr. Weinreb and Dr. Coleman with Cong. Gene Green (D-TX), Chair of the Congressional Vision Caucus

Left to right: Arthur Sit, M.D. (Mayo Clinic College of Medicine), Sen. Amy Klobuchar (D-MN), an ardent supporter of NIH funding increases, and Thomas Samuelson M.D. (University of Minnesota)

Andrew Adelson, M.D. and Howard Weiss, M.D., M.P.H., met with Keisha Brooks-Coley (center) in the office of Sen. Barbara Mikulski (D-MD), a Senate Appropriator in whose state the NIH campus is located

Left to right: Sarah Chin, office of Sen. Herb Kohl (D-WI), with Paul Kaufman, M.D., Sen. Kohl, an appropriator with jurisdiction over NIH funding and defense-related vision research funding, also chairs the Senate Special Committee on Aging.

Advocacy Day Program Co-Chair Ted Krupin, M.D. (Northwestern University) emphasizes the key messages during the preparatory breakfast session

NAEVR Executive Director James Jorkasky and Scott Christensen, President of The Glaucoma Foundation and the World Glaucoma Patient Association, which initiated World Glaucoma Day

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Masthead photography courtesy of the **National Eye Institute**

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THE RIGHT TO SIGHT

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VISION 2020 is all about collaboration and partnership. Our many members work together to eliminate avoidable blindness. To register as a supporter of VISION 2020 and to receive monthly updates by email, SIGN UP HERE!

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VISION 2020
THE RIGHT TO SIGHT

"Our vision is the elimination of the main causes of avoidable blindness by 2020, in order to give all people in the world the right to sight"

Home / **World Sight Day**

The global day for awareness of blindness and vision impairment

World Sight Day (WSD) is an annual day of awareness held on the second Thursday of October, to focus global attention on blindness and vision impairment.

Included on the official World Health Organization calendar, WSD is co-ordinated by IAPB under the VISION 2020 Global Initiative. The theme, and certain core materials are generated by IAPB. All events are organised independently by members and supporters.

World Sight Day 2007 | World Sight Day 2008

On World Sight Day, VISION 2020 members *work together* to:

- Raise public awareness of blindness as a major international public health issue
- InfluenceGovernments/Ministersof Health in developing countries to participate in and designate fundsfor national blindness prevention programmes
- Educate target audiences about blindness prevention, about VISION 2020 and its activities, and to generate support for programme activities of member organisations

International Key Messages

- Approximately 314 million people suffer serious vision impairment
- Of these, **45 million people are blind** and 124 million have low vision
- 153 million people's vision impairment is due to uncorrected refractive errors. In most cases, normal vision could be restored with eyeglasses or contact lenses
- Yet **75% of blindness is avoidable** - i.e. treatable and/or preventable
- 90% of vision impaired people live in developing countries
- Restorations of sight, and blindness prevention strategies are among the most cost-effective interventions in health care
- Infectious causes of blindness are decreasing as a result of public health interventions and socio-economic development. Blinding trachoma now affects fewer than 80 million people, compared to 360 million in 1985
- Aging populations and lifestyle changes mean that chronic blinding conditions such as diabetic retinopathy are now rising
- Women face a greater risk of vision loss than men
  Without proper interventions, 76 million people could be blind by 2020
- Without effective, major intervention, the number of blind people worldwide is projected to increase to 76 million by 2020

PRESS RELEASE

FOR IMMEDIATE RELEASE
June 25, 2007

Contact: James F. Jorkasky
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jamesj@eyeresearch.org

NAEVR CITES NEI-FUNDED RESEARCH ON PROTECTIVE EFFECT OF OMEGA-3 FATTY ACIDS ON RETINAL DISEASE AS DRAMATIC EXAMPLE OF NEED FOR INCREASED FY2008 NIH FUNDING

(Washington, D.C.) Today, the National Alliance for Eye and Vision Research (NAEVR) cited a just-released National Eye Institute (NEI)-funded study which demonstrates the protective effect of omega-3 polyunsaturated fatty acids against retinopathy (deterioration of the retina) in mice as a dramatic example of the types of groundbreaking research that must be adequately funded by the federal government in Fiscal Year (FY) 2008 appropriations for the National Institutes of Health (NIH) currently being considered by Congress.

The study, published in the July 2007 edition of the journal *Nature Medicine,* is important for several reasons. Retinopathy in the mouse shares many characteristics with Retinopathy of Prematurity (ROP) in humans, a disease of premature infants in which blood vessels proliferate in the retina, leading to bleeding, scarring, and potential blindness. Following up on this finding, NEI will fund a clinical trial to test the effects of omega-3 supplements in premature infants.

The study also found that this disease process may also apply to both diabetic retinopathy and age-related macular degeneration (AMD), the latter of which is the leading cause of vision loss in Americans. The NEI is currently conducting the second phase of its Age-Related Eye Disease Study (AREDS2), which will assess the effect of omega-3 fatty acids on the progression of AMD. The first phase of AREDS demonstrated that antioxidant vitamins and minerals reduced the progression of the moderate stage of AMD to the severe stage of the disease by 25 percent.

"As noted by this just-released study's co-lead author and NEI scientist Dr. John Paul SanGiovanni, the NEI is identifying low cost and widely available nutrient-based treatment approaches that may show merit in future research on diseases that damage retinal blood vessels and nerve cells," stated NAEVR Executive Director James Jorkasky, who reiterated that disease preemption and prevention are hallmarks of the NIH research paradigm for the 21st century, as described by NIH Director Dr. Elias Zerhouni.

On June 22, NEI Director Dr. Paul Sieving testified before the Senate Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittee, focusing his comments on the vision public health challenge resulting from the aging of the baby boom generation. "With

research ranging from ROP in infants to AMD in seniors, the NEI affects and benefits Americans at all stages of life," said Jorkasky, who added that this is a major justification for NIH/NEI funding increases currently being considered in Congress.

The FY2008 Senate LHHS appropriations bill, approved by the full Senate Appropriations Committee on June 21, increases NIH funding by $1 billion to $29.9 billion and NEI by $14.8 million to $682 million. The House bill, marked up in Subcommittee on June 7, increases NIH funding by $750 million to $29.6 billion and NEI by $9.9 million to $677 million. Both are significant increases over the President's FY2008 budget proposal.

The National Alliance for Eye and Vision Research (NAEVR) is a non-profit advocacy coalition comprised of 55 professional, consumer, and industry organizations involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education for eye and vision research sponsored by the National Institutes of Health (NIH), the National Eye Institute (NEI), and other federal research entities. Visit NAEVR's Web site at www.eyeresearch.org.

Appendix K

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PRESS RELEASE

FOR IMMEDIATE RELEASE
March 26, 2008

Contact: James F. Jorkasky
Executive Director
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jamesj@eyeresearch.org

NAEVR's HOUSE TESTIMONY REQUESTS FY2009 NIH AND NEI FUNDING AT $31 BILLION AND $711 MILLION, RESPECTIVELY, CITING LATEST NEI RESEARCH AND COLLABORATIONS

(Washington, D.C.) Today, the National Alliance for Eye and Vision Research (NAEVR) submitted written testimony to the House Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittee requesting Fiscal Year (FY) 2009 National Institutes of Health (NIH) and National Eye Institute (NEI) funding of $31 billion and $711 million, respectively, or a 6.6 percent increase to match biomedical inflation and to begin restoring purchasing power lost in the past five funding cycles. NAEVR's comments cited the latest NEI–funded research and collaborations, as follows:

- In March 2008, NEI-funded researchers announced that two major eye diseases and leading causes of blindness—age-related macular degeneration (AMD) and diabetic retinopathy (DR)—can be reversed or even prevented by drugs that activate a protein found in blood vessels. The protein, Robo4, was activated in mouse models that simulate AMD and DR and treated and prevented the diseases by inhibiting abnormal blood vessel growth and by stabilizing blood vessels to prevent leakage. Since this research into the "Robo4 Pathway" used animal models associated with these diseases that are already used in drug development, the time required to test this approach in humans could be shortened, expediting approvals for new drug therapies.

- In March 2008, NEI's *Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease* reported that 71 percent of respondents indicated that loss of their eyesight would rate as a "10" on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life. This research builds upon public opinion polls conducted over the past 40 years in which Americans have consistently identified fear of vision loss as second only to fear of cancer.

- In March 2008, the NEI collaborated with the Food and Drug Administration's (FDA) Center for Drug Evaluation and Research (CDER) and Center for Devices and Radiological Health (CDRH) on a meeting to consider alternative endpoints in clinical trials for drugs and devices used to diagnose and treat glaucoma, the second leading cause of preventable vision loss in all Americans and the leading

> cause of irreversible vision loss in African Americans and Hispanics. The meeting followed a November 2006 joint NEI/FDA-CDER meeting on clinical endpoints in AMD and DR clinical trials. As NAEVR noted, this collaboration between the NEI and FDA represents the cost-effectiveness of NEI funding, as its research results may ultimately shorten the time and cost associated with clinical trials, as well as facilitate the approval of new diagnostics and therapies for patients.

In releasing the testimony, NAEVR Executive Director James Jorkasky made the following statement:

> "This testimony emphasizes the relevance of the latest NEI research and its immediacy in addressing the burden of eye disease and vision impairment growing ever larger as the first wave of 78 million Baby Boomers reach their 65th birthday in 2010. It also highlights NEI's collaborations within the NIH, with other Department of Health and Human Services (DHHS) agencies, and with private funding organizations. The NEI must be adequately funded to initiate promising new research, to pursue results that have emerged from previous breakthroughs, and to offer up its 'fair share' of funding in its extensive collaborations. As a result, NAEVR requests a 6.6 percent increase for both NIH and NEI funding in Fiscal Year 2009, or $31 billion and $711 million, respectively, to match the biomedical inflation rate and to begin restoring purchasing power lost over the past five funding cycles."

The National Alliance for Eye and Vision Research (NAEVR) is a non-profit advocacy coalition comprised of 55 professional, consumer, and industry organizations involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education for eye and vision research sponsored by the National Institutes of Health (NIH), the National Eye Institute (NEI) and other federal research entities. Visit NAEVR's Web site at www.eyeresearch.org.

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PRESS RELEASE

FOR IMMEDIATE RELEASE
September 12, 2007

Contact: James F. Jorkasky
Executive Director
240-221-2905
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U.S. CENSUS DATA ON WORKING SENIORS DEMONSTRATES IMPORTANCE OF VISION HEALTH; NAEVR EDUCATES HILL ON IMPACT OF AGING EYE DISEASE AND VISION RESEARCH FUNDING

(Washington, D.C.) Today, National Alliance for Eye and Vision Research (NAEVR) Executive Director James Jorkasky cited the just-released U.S. Census data on the number of individuals 65 and older that were still working as evidence of the importance of good senior vision health to the nation, as well as the critical need for adequate federal research funding on aging eye disease. The U.S. Census data for 2006 reported that, nationally, one in four individuals age 65-74 was still working, as compared to one in five in 2000. The percentage was even higher in the Washington, D.C. region, where about one-third of people in that age range continued to work.

"Senior productivity is just one of the many reasons that research into aging eye disease is so important, " stated Jorkasky, who noted that adult vision loss is associated with increased healthcare costs, reduced independence, diminished quality of life, increased depression, and accelerated mortality. "Research to delay, prevent, and treat aging eye disease will not only result in seniors living more productive lives, but can also reduce Medicare costs."

To ensure that legislators are fully aware of the impact of aging eye disease, NAEVR, in partnership with the Alliance for Aging Research, will release the first-ever volume of the Alliance's *The Silver Book: Chronic Disease and Medical Innovation in An Aging Nation* dedicated to aging eye disease—*The Silver Book: Vision Loss*. The release event will be held on Tuesday, September 25, from 12 Noon – 1:15 pm in the Russell Senate Office Building Room 385. It occurs during Worldwide Age-related Macular Degeneration (AMD) Awareness Week 2007 with the theme of *The Face of AMD,* and is being held in conjunction with the Congressional Vision Caucus, Prevent Blindness America, and AMD Alliance International.

Featured speakers include: National Eye Institute (NEI)-funded researcher Michael Gorin, M.D., Ph.D. (Jules Stein Eye Institute/UCLA), who will discuss current research into aging eye disease; economist David Rein, Ph.D. (RTI International), who will address the economic burden of eye disease; and patient Hyman Shapiro, J.D., who will describe living with AMD. NAEVR's Executive Director James Jorkasky will join Alliance for Aging Research's Executive Director Dan Perry in moderating the event.

More than 38 million Americans age 40 and older are blind, visually impaired, or have an age-related eye disease. The economic impact of adult vision loss is astonishing, with the United States costs exceeding $51 billion—a huge share of the $68 billion annual cost of all vision impairment and eye disease, as estimated by the National Eye Institute (NEI) within the National Institutes of Health (NIH).

Appendix L

The **National Alliance for Eye and Vision Research (NAEVR)** is a nonprofit advocacy coalition comprised of 55 professional, consumer, and industry organizations involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education for eye and vision research sponsored by the National Institutes of Health (NIH), the National Eye Institute (NEI), and other federal research entities. Visit NAEVR's Web site at **www.eyeresearch.org**.

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September 2007

NAEVR Releases *Silver Book: Vision Loss*® at Congressional Briefing Highlighting the Impact of Age-Related Eye Diseases

On September 25, the National Alliance for Eye and Vision Research (NAEVR), in partnership with the Alliance for Aging Research, hosted a Congressional briefing to release a new volume of ***The Silver Book®: Chronic Disease and Medical Innovation in an Aging Nation*** dedicated to age-related eye disease. Entitled ***The Silver Book®: Vision Loss***, it presents the latest data on the significant health and economic burden of age-related eye diseases and demonstrates the potential for innovative treatments emerging from research. It is available on-line at **www.silverbook.org/visionloss.**

The release of ***The Silver Book®: Vision Loss*** coincided with Worldwide Age-Related Macular Degeneration (AMD) Awareness Week 2007. Each year, an estimated 200,000 Americans develop AMD, the leading cause of vision loss in which abnormal blood vessels or protein deposits cause progressive damage to the macula, the central part of the retina responsible for providing sharp central vision.

Moderators for the briefing were Daniel Perry, Executive Director of the Alliance for Aging Research, and James Jorkasky, NAEVR Executive Director. Featured speakers were Michael Gorin, M.D., Ph.D. (Jules Stein Eye Institute, University of California Los Angeles), David Rein, Ph.D, M.P.A. (Research Triangle Institute [RTI] International), and Hyman Shapiro, J.D., an attorney and AMD patient. The briefing was co-sponsored by the Congressional Vision Caucus, Prevent Blindness America, and AMD Alliance International.

Perry conveyed the impact that the baby boom generation will have on the prevalence of age-related diseases and the economy. It is "exactly three years, three months, and five days until…the day the first wave of the 78 million post-war Baby Boomers celebrate their 65th birthday," he said. He added that, each day for 18 years afterwards, about 10,000 Americans will turn 65, leading to a huge impact on the Medicare budget as additional funds are needed to treat age-related diseases, including those in the eye.

According to NAEVR's Jorkasky, the data in ***The Silver Book®: Vision Loss*** support the importance of research conducted by the National Eye Institute (NEI) within the National Institutes of Health (NIH) for the estimated 38 million Americans over age 40 experiencing blindness or an age-related eye disease, such as AMD, glaucoma, diabetic retinopathy, and cataract. This number is expected to grow to more than 50 million Americans by year 2020.

The release of *The Silver Book®: Vision Loss* coincided with Worldwide Age-Related Macular Degeneration (AMD) Awareness Week 2007.

Left to right: Alliance for Aging Research's Dan Perry, research speaker Dr. Michael Gorin, and NAEVR's James Jorkasky

Dr. Michael Gorin

Dr. Gorin discussed how genetics research, especially NIH's Human Genome Project, has dramatically improved understanding of the genetic basis of AMD and other vision disorders, and how additional research can help with remaining challenges. Gorin discussed several advances in AMD that resulted from innovative research, including the use of anti-VEGF (Vegetative Endothelial Growth Factor) compounds to halt abnormal blood vessel growth in the retina. As Gorin noted, anti-VEGF for treating AMD was a direct outcome of earlier NIH-funded research by Harvard's Dr. Judah Folkman into angiogenesis—the proliferation of new blood vessels—in cancer tumors. The first generation of Food and Drug Administration (FDA)-approved anti-VEGF ophthalmic drugs are turning out to be so effective that they are even reversing vision loss in some patients. Gorin also described new, non-invasive, high-resolution imaging devices that provide eye care professionals and researchers with extraordinary images of the retina for making accurate diagnoses of diseases and for tracking the effectiveness of treatments.

Alliance
FOR AGING RESEARCH

Dr. David Rein

Dr. Rein, a public health research economist and leader in quantifying costs associated with age-related eye diseases, described how the $51.4 billion spent annually in the U.S. on vision disorders in Americans age 40 and older exceeds the amount spent on several other common diseases such as stroke, breast cancer, and HIV. The NEI, which estimates the annual total cost burden for vision impairment and eye disease at $68 billion, also estimates that by 2020 the number of cases of age-related eye diseases will increase by 47 percent for cataracts and by 76 percent for diabetic retinopathy.

Rein stated that, although federally-funded research programs—including those at NEI, the Department of Veterans Affairs (VA), and the Centers for Disease Control and Prevention (CDC)—have resulted in technological advances that increase patient welfare, these technologies are also associated with substantial costs that must be weighed with the concomitant benefit derived, the value of which could be equal, if not more significant. Additional research is needed to demonstrate which interventions provide the greatest impact per health care dollar spent.

Dr. David Rein addresses Congressional staff

"It is often depresssion rather than the vision loss that establishes a patient's level of function," said Gorin.

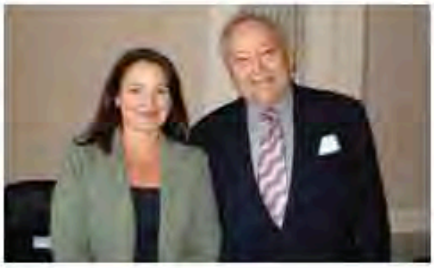
Hyman Shapiro

In 1988 at the age of 61, Mr. Shapiro was diagnosed with AMD. He described what it is like to live with the disease and the consequences of older treatments that likely saved him from total blindness yet left his vision compromised. Despite having only limited vision in one eye, Shapiro continues to be an active member in his suburban DC community where he was recently invited to serve on the Montgomery County (Maryland) Board of Property Review. He represents the growing number of people over 65 who are working and actively contributing to their communities despite physical limitations.

Mr. Shapiro is enrolled in the Age-Related Eye Disease Study (AREDS), an NEI-funded study that demonstrated that high levels of dietary anti-oxidants and zinc can reduce the risk of progression to advanced AMD by a factor of 25 percent. He is hopeful that the dietary supplements, coupled with anti-VEGF ophthalmic drug treatment, can maintain his remaining vision.

Although Mr. Shapiro has trouble performing simple tasks like reading a price tag or putting toothpaste on the toothbrush, he says he "concentrates on what I can do, not on what I cannot do." He believes that the same attitudes among policymakers and scientists that led to curing certain cancers, conquering polio, and managing AIDS will lead to saving and restoring vision and maintaining the quality of life in aging Americans.

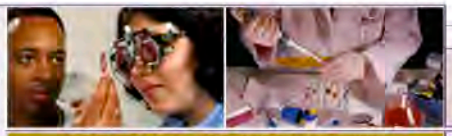
Mr. Shapiro is one of the lucky ones who has remained positive and productive despite AMD. Dr. Gorin pointed out that over 30 percent of people with AMD suffer from clinical depression. "It is often the depression rather than the vision loss that establishes a patient's level of function," said Gorin.



Left to right: Joanne Olson (Association for Research in Vision and Ophthalmology) and patient advocate Hyman Shapiro

About NAEVR

The National Alliance for Eye and Vision Research (NAEVR) is a non-profit advocacy coalition comprised of 55 professional, consumer, and industry organizations involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education for eye and vision research sponsored by the National Institutes of Health (NIH), the National Eye Institute (NEI), and other federal research entities. Visit NAEVR's Web site at www.eyeresearch.org



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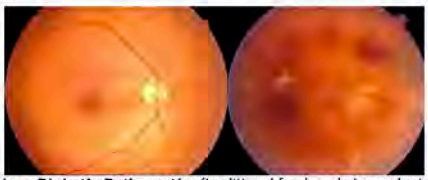
Using Real-time OCT, AEVR Educates Capitol Hill on Visual Imaging Technologies Revolutionizing the Diagnosis and Treatment of Eye Disease

Attendees view real-time OCT images

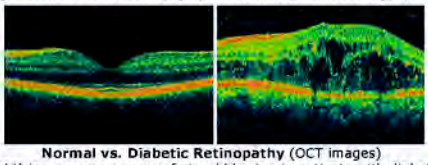
The next generation of Optical Coherence Tomography (OCT), a powerful diagnostic imaging technology that has emerged from collaborative research between the National Eye Institute (NEI) and the National Institute of Biomedical Imaging and Bioengineering (NIBIB) within the National Institutes of Health (NIH), is already revolutionizing an eye care practitioner's ability to diagnose and monitor treatment of major eye diseases faster, more accurately, at lower cost, and with less discomfort for the patient than ever before, Alexander Walsh, M.D., told members of Congress and staffers in a February 26 Capitol Hill briefing.

Topcon Medical Systems' Aaron Graham performs a retinal scan

"OCT has changed everything we do in ophthalmology," said Walsh, an assistant professor of ophthalmology at the University of Southern California and director of the Doheny Eye Institute's Imaging Exploration and Software Engineering Laboratory. "It represents an objective, standardized method for making a diagnosis and a quantitative way to monitor treatment progress and outcomes." Walsh spoke at this briefing sponsored by the Alliance for Eye and Vision Research (AEVR) and held in conjunction with the Coalition for Imaging and Bioengineering Research (CIBR), the American Institute for Medical and Biological Engineering (AIMBE), the Association for Research in Vision and Ophthalmology (ARVO), and the Ad Hoc Group for Medical Research.



Normal vs. Diabetic Retinopathy (traditional fundus photography images)
Early diagnosis is critical in patients with diabetic retinopathy since patients with healthy retinas (left) that receive timely laser treatments have a better chance of visual preservation than patients with diagnoses that are missed (right) and who often become legally blind



Normal vs. Diabetic Retinopathy (OCT images)
Retinal swelling (right) is a common cause of visual blurring in patients with diabetic retinopathy. The quantitative measurement of retinal thickness by OCT can improve management of therapies and decrease unnecessary or costly treatments.

OCT is a non-invasive, high-speed, high-resolution imaging technology that can now display a three-dimensional, cross-sectional view of the retina, not just the superficial view of its surface provided by conventional imaging technologies. OCT systems—no bigger than many instruments already in an ophthalmologist's office—can capture an image painlessly in just seconds. Layers of the retina can then be separated on the computer screen to visualize and diagnose eye diseases, such as age-related macular degeneration (AMD, the leading cause of blindness in older Americans), diabetic retinopathy (the leading cause of blindness among working-age Americans), and glaucoma (the leading cause of vision loss in African Americans and Hispanics). "With OCT, we can now see minute tissue layers deep inside the eye to determine what might well have been missed before," said Walsh, who demonstrated the speed and simplicity of an OCT scan with a live demonstration using a next-generation system provided by Topcon Medical Systems.

Unlike earlier tools, OCT creates color-coded numerical thickness maps of the retina that resemble topographic maps of mountainous terrain. These numbers allow practitioners to document changes in disease progression or the effects of treatment from visit to visit, which facilitates earlier diagnosis and better management of therapies and can mitigate both the risks and costs of over- or under-treatment. In fact, numbers are an essential advantage of OCT, said Walsh, who likened it to when individuals know their cholesterol levels or blood pressure readings and can compare them to benchmarks and take steps to reduce them. "Quantifying the state of the eye's interior leaves less to subjective judgment and helps both practitioners and patients understand the disease and measure treatment progress," he stated.

The clinical applications of OCT that have been investigated and proven by federally-funded research demonstrate the cost-effectiveness of this research. For example:

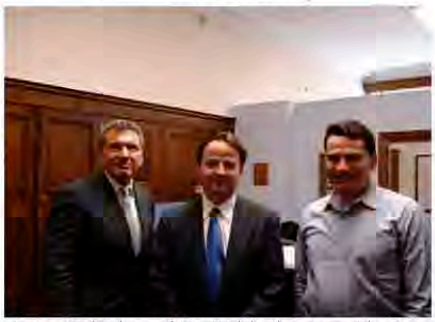
- OCT provides unparalleled visualization and measurement of retinal changes that can be coupled with a functional measurement of vision, maximizing the use of evidence-based medicine in eye care.
- The Food and Drug Administration (FDA) is increasingly considering OCT as an outcomes measure in clinical trials for new treatment's, reducing costs by requiring fewer patients and taking less time, thus speeding new diagnostic tests or treatments to patients.
- CT can save money as well as eye sight, as diagnoses and therapies based on this technology can delay, save, and prevent expenditures to the Medicare program, especially with the epidemic of age-related eye diseases due to an aging population.

"The need for OCT grows all the time," said Walsh, who added that ongoing collaborations among the NEI, NIBIB, academic researchers, and industry are leading to further refinements in the technology. "Although currently used primarily in a retinal specialist's office, OCT has widespread potential as a cost-effective tool to screen for AMD, diabetic retinopathy, and glaucoma," he said, while also acknowledging that the technology is just beginning to expand into other medical fields, such as cardiology, dermatology, and gastroenterology.

Cong. David Hobson (R-OH, left), a House Appropriator, shares his family's experience with vision loss with AEVR Executive Director James Jorkasky

CIBR President Renee Cruea offered a welcome and commented that, with respect to medical imaging, "We can be proud of the state of the science now, but we also have to be aware of how much further we have to go."

Prior to the briefing, Dr. Walsh met with Melissa Bez in the office of Cong. Henry Waxman (D-CA) of the House Energy and Commerce Committee, with authorization jurisdiction over the NIH



James Jorkasky and Dr. Walsh also met with Sean McCluskie (right) in the office of Cong. Xavier Becerra (D-CA), whose district includes the USC campus.

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PRESS RELEASE

FOR IMMEDIATE RELEASE
February 14, 2008

Contact: James F. Jorkasky
Executive Director
240-221-2905
jamesj@eyeresearch.org

THE INDEPENDENT BUDGET FOR VA FUNDING RECOMMENDS EYE AND VISION ELIGIBIITY IN THE FY2009 DOD/PRMRP PROGRAM, URGES VA-DOD EYE TRAUMA FUNDING

(Washington, D.C.) Today, the National Alliance for Eye and Vision Research (NAEVR) announced that *The Independent Budget,* an annual set of recommendations to Congress regarding Department of Veterans Affairs (VA) funding, has made recommendations regarding Special Needs Veterans, specifically Blinded Veterans, for the Fiscal Year (FY) 2009 funding process. *The Independent Budget*–developed by AMVETS, Disabled American Veterans, Paralyzed Veterans of America, and the Veterans of Foreign Wars, and supported by 54 other organizations–recommends that:

- The Congressionally Directed Peer Medical Research Program, in which eye and vision research has been listed as eligible for funding within the $50 million Peer Reviewed Medical Research Program (PRMRP), must continue to include eye and vision research in the Department of Defense (DOD appropriation for FY2009, and Congress should authorize more VA-DOD research funding on eye trauma.

- Congress must create a DOD military eye trauma “Center of Excellence” and “Eye Trauma Registry” that electronically exchange information with eye care professionals within the VA to improve seamless transition.

NAEVR has distributed its FY2009 DOD/PRMRP listing request on Capitol Hill and has begun working with its champions in the House and Senate Defense Appropriations Subcommittees. Eye and vision research has been listed in FY2006-FY2008 for this program, which enables researchers in eligible areas to compete for a pool of $50 million of peer-reviewed funding. In FY2006, its first year of eligibility, the vision community submitted 52 grant requests to the DOD, or 8 percent of all submissions, and was awarded 6 grants out of the 51 issued, for a funding total of $5.4 million, or 12 percent. Examples of this research include: corneal healing, as well as ways to improve corneal transplantation by regulating the lymphatic pathway servicing the cornea; corneal wound infection control; laser injuries; and support for ongoing work on a “Retinal Implant” to restore vision through electronic stimulation of the retina.

Appendix O

Regarding eye trauma, the FY2008 Defense Authorization Act included provisions of the *Military Eye Trauma Treatment Act* which would:

- Create a "Center of Excellence" within the DOD that would collaborate with the VA on a comprehensive approach to the prevention, diagnosis, mitigation, treatment, and rehabilitation of eye injuries and trauma, including a "Military Eye Injury Registry" to track the diagnosis and treatment of each significant eye injury incurred by a member of the armed forces while on active duty; and

- Create a joint DOD/VA program to coordinate on all aspects of visual dysfunction related to Traumatic Brain Injury (TBI), including screening, diagnosis, rehabilitative management, and research.

NAEVR supported this legislation, and will work with all appropriate federal and private entities to ensure that both the "Center of Excellence" and "Military Eye Trauma Registry" are established.

The National Alliance for Eye and Vision Research (NAEVR) is a non-profit advocacy coalition comprised of 55 professional, consumer, and industry organizations involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education for eye and vision research sponsored by the National Institutes of Health (NIH), the National Eye Institute (NEI) and other federal research entities. Visit NAEVR's Web site at www.eyeresearch.org.

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Eye and Vision Breakthroughs: Keep the Research Drive Alive!

By Hand Delivery – March 26, 2008

The Honorable Tom Harkin, Chairman
Senate LHHS Appropriations Subcommittee
731 Senate Hart Office Building
Washington, DC 20510

Dear Senator ~~Harkin~~ Tom:

I am writing to request a meeting with you on Wednesday, April 16, when I am in Washington, D.C, for meetings of the Institute of Medicine.

I want to personally express the eye and vision research community's appreciation for your bipartisan leadership with Senator Specter for a Fiscal Year 2009 National Institutes of Health (NIH) funding increase.

I have read the statement accompanying Senate Amendment 4203, which was overwhelmingly passed by the Senate on March 13. I noted the acknowledgment of the National Eye Institute's (NEI) limitations on conducting epidemiological studies due to budget constraints. In the attached comments to the House LHHS Appropriations Subcommittee, NAEVR cites a number of other "missed opportunities" at NEI, including limits to: expanding ocular gene-based studies, pursuing promising new protocols in the Diabetic Retinopathy Clinical Research Network, and forming Clinical Research Networks for Age-related Macular Degeneration (AMD) and Neuro-ophthalmology.

NAEVR's comments highlight a number of just-released NEI research findings, as well as recent collaborations, including an early March 2008 meeting between the NEI and the Food and Drug Administration (FDA) to consider alternative endpoints for glaucoma clinical trials, which could reduce the time and cost of these trials and speed new therapies to patients. A summary of that event is attached.

I have asked NAEVR Executive Director James Jorkasky to coordinate with your office on a potential visit. Jim is at jamesj@eyeresearch.org or 240-221-2905. I hope that your very busy schedule can accommodate a brief visit.

Sincerely,

Stephen J. Ryan

Stephen J. Ryan, M.D.
NAEVR President

cc: Ms. Ellen Murray, Mr. Erik Fatemi

12300 Twinbrook Parkway Suite 250, Rockville, Maryland 20852-1606 T 240-221-2905 F 240-221-0370 eyeresearch.org

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Association of Vision Science Librarians
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Women's Eye Health Task Force

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Eye and Vision Breakthroughs: Keep the Research Drive Alive!

By Email

July 12, 2007

Hanna Doerr
Health Policy Adviser
Office of the Honorable Nancy Pelosi, House Speaker
US Capitol, Room H-419G
Washington, DC 20510

Dear Hanna:

Thank you for meeting with NAEVR's Jim Jorkasky and David Epstein and me. I am pleased to continue NAEVR's close working relationship with the Speaker's office, following up on the October 2006 meeting with Dr. Primus.

I was delighted to hand deliver to you a copy of NAEVR's letter to House Appropriations Committee Chairman Cong. David Obey noting that we had written to all Committee members urging support for the FY2008 LHHS appropriations bill. NAEVR appreciates the Democratic leadership's commitment to restoring funding for medical research at the National Institutes of Health (NIH), generally, and the National Eye Institute (NEI), specifically, within the budget resolution and LHHS allocation.

Since Dr. Primus had previously indicated the Speaker's emphasis on disease prevention, I appreciated the opportunity to discuss the NEI-funded research into the potential preventive effect of antioxidant vitamins, minerals, and omega-3 fatty acids on retinal disease. Jim will ensure to keep you apprised of the latest developments emerging from this research.

Sincerely,

Stephen J. Ryan, M.D.
President, NAEVR Board of Directors

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