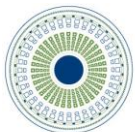


Partnerships to Advance Advocacy and Increase Funding in Vision Research

**NAEVR/AEVR Presentation at the
Health Research Alliance Members Meeting
Creating Networking and Partnering Opportunities Session
September 26, 2019**



Alliance For Eye
And Vision Research

AEVR

Educating about the Value of Vision Research



NAEVR

National Alliance For
Eye And Vision Research

Serving as Friends of the National Eye Institute

About NAEVR and AEVR Timeline

1993:

- Alliance for Eye and Vision Research (AEVR) founded as 501c3 educational foundation to raise awareness about value of federally funded vision research at the National Institutes of Health (NIH) and National Eye Institute (NEI).

1997:

- National Alliance for Eye and Vision Research (NAEVR) founded as 501c4 “social welfare” organization to advocate for federally funded vision research--initially for NIH/NEI, then for DOD/VA in 2004, *21st Century Cures Act* in 2015. NAEVR has no direct political activity.

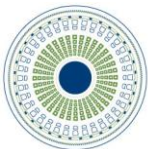
2008:

- AEVR/NAEVR celebrate 15th anniversary, secure House/Senate resolutions recognizing NEI 40th anniversary, declaring 2010-2020 as “Decade of Vision.”

2018:

- AEVR/NAEVR celebrate 25th anniversary, emphasize NEI’s 50th anniversary.

**Together, NAEVR and AEVR combined serve as the 50+ member privately funded
“Friends of the NEI”**



Alliance For Eye
And Vision Research
AEVR



NAEVR
National Alliance For
Eye And Vision Research

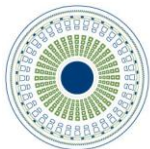
Vision and Chronic Disease Public Health Concerns will Only Grow

Demographics: *Decade of Vision 2010-2020*

- The first wave of 78 M Baby Boomers will turn 65 in 2010, and each day for 18 years afterwards, about 10,000 Americans will turn 65.
- The fast-growing Hispanic and African American populations experience a disproportionate risk/incidence eye disease, often with concomitant healthcare access challenges.
- Vision will become increasingly impacted by other chronic conditions or by the therapies used to treat them.

Public Policy: Vision Impairment and Eye Disease is a Growing Public Health Problem

- As the funders of both biomedical and disease prevention research, Congress will want to see better coordination of federal agency activities to impact patients' lives.
- The public will demand treatments and therapies that enable them to be productive, independent, and maintain/improve quality of life.



Alliance For Eye
And Vision Research
AEVR



NAEVR
National Alliance For
Eye And Vision Research

FY2018 Vision Research Funding-- All Sources

Estimated Total of FY2018 US Vision Research Funding: \$4 B

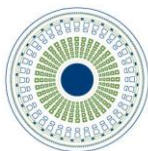
Federal Components (\$900 M):

- **\$740 M (NEI Extra/Intramural: 96% of \$770.5 M operational budget)***
- **\$100 M (\$68 M BRAIN Initiative, \$4 M Regenerative Medicine, \$4 M Alzheimer's, \$25 M Other NIH I/Cs, such as diabetes imaging, neuroscience;**
- **\$ 25 M (DOD/Vision Trauma Research, other DOD programs)**
- **\$ 20 M (VA Intramural Research, TBI centers)**
- **\$ 10 M (Depts. of Energy/National Science Foundation)**
- **\$ 4 M (Vision Loss Prevention Research/CDC, HRSA)**
- **\$ 2 M (Natl Institute on Disability/Independent Living/Rehab)**

**Private Foundation Funding (estimate): \$75 M
(excludes academic institution philanthropy —??)**

Industry (estimate): \$3 B

*** FY2019 NEI Operating Budget is \$793.8 M (\$796.5 M enacted)**



Alliance For Eye
And Vision Research
AEVR



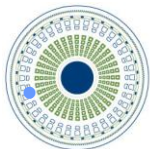
NAEVR
National Alliance For
Eye And Vision Research

Example: Annual Convening of Public/Private Partners

AEVR/NAEVR membership includes professional societies in ophthalmology and optometry, patient and consumer groups, private funding foundations, and industry.

2014:

- **AEVR/NAEVR Member Research to Prevent Blindness (RPB) proposes and funds first “Convening of Private Funding Foundations,” in conjunction with AEVR/NAEVR.**
- **Held in September 2014 in conjunction with National Press Club release of major AEVR study – conducted with Research!America and supported by a grant from RPB—which reported that Americans across all demographics fear loss of vision (published in *JAMA Ophthalmology*).**
- **Discussions so successful that an annual “Convening” planned for 2015, with several private foundations funding it and event moved to March to accommodate a NAEVR Advocacy Day during appropriations season.**



Alliance For Eye
And Vision Research
AEVR

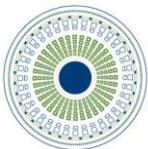


NAEVR
National Alliance For
Eye And Vision Research

Example: Annual Convening of Public/Private Partners

2015-2019... and beyond, program expanded to include:

- **30+ private funding foundations with emphasis on vision biomedical research or vision loss prevention research.**
- **Participation by public funders (NEI, DOD, VA, CDC) to address scientific opportunity and unmet need to identify opportunities for collaboration.**
- **Presentation by professional societies of “hot topics” in vision research (Registries, Artificial Intelligence, Vision Restoration, Vision Relation to other Chronic Diseases) and potential role for private funding.**
- **Discussions about private sector implementation of the September 2016 National Academies of Sciences, Engineering, and Medicine’s Report *Making Eye Health a Population Health Imperative: Vision for Tomorrow*.**
- **Maintain dedicated time for interaction solely between the private funding foundations in issue-specific breakout workshops.**



Alliance For Eye
And Vision Research
AEVR



NAEVR
National Alliance For
Eye And Vision Research

Example: Annual Convening of Public/Private Partners

2015-2019... and beyond, program expanded to include:

- **Greater participation in the NAEVR-hosted Advocacy Day focusing on:**
 - the important role of the foundation in the district/state,
 - funding support for early-stage investigators, focused areas of research, and bridge funding during delayed appropriations due to a Continuing Resolution.



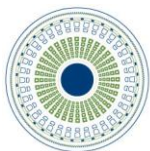
Brian Hofland, PhD (Research to Prevent Blindness) with Cong. Nita Lowey (D-NY),
Chair of the House
Appropriations Committee



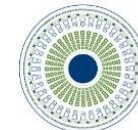
Convening of Private Vision Research Funding Foundations with federal agencies which support vision research (NEI) and vision loss prevention research and vision surveillance (Centers for Disease Control and Prevention, CDC), as well as approve new ophthalmic drugs and devices (Food and Drug Administration)



Torrey DeKeyser (Eyesight Foundation of Alabama) with Senator Doug Jones (D-AL), who serves on the Senate Health, Education, Labor & Pensions Committee, which has oversight over the NIH



Alliance For Eye
And Vision Research
AEVR

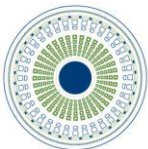


NAEVR
National Alliance For
Eye And Vision Research

Example: Annual Convening of Public/Private Partners

Deliverables

- **New funding opportunities for researchers, often jointly funded by two or more foundations to leverage funding or focus of research:**
 - **Low Vision Research**
 - **Catalyst Award in Age-Related Macular Degeneration Research**
 - **Glaucoma Research**
 - **Early-stage Investigators (*Emerging Vision Scientists*)**
 - **Focused studies using Registry data**
 - **Endowed Research Director position at major academic center**
- **Release by public funding sources of new programs or tools, with emphasis on engaging private foundations in dissemination and use.**
 - **CDC Surveillance Activities result in new national and state-by-state fact sheets on eye disease prevalence.**
 - **NEI announce Regenerative Medicine Awards (requires match funding).**



Alliance For Eye
And Vision Research
AEVR

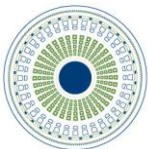


NAEVR
National Alliance For
Eye And Vision Research

Example: Annual Convening of Public/Private Partners

2020 Deliverable – Vision Research Messaging

- **Participants express concern about ongoing and effective messaging about vision loss and the value of vision research to several stakeholders, including patients, legislators and policymakers (and their aides!), the media, and for-profit technology companies (not just manufacturers, but service providers.)**
- **Realize that any current campaign needs social media component and concomitant expertise.**
- **Makes more sense to develop as a group and share with the vision community.**
- **Kick-off in September 2019 with RFP request, project results by mid-year.**
 - **Messaging for tail-end of FY2021 appropriations process.**
 - **Potentially use in “Year 2020, 2020 Vision” awareness campaigns.**



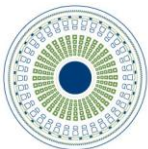
Alliance For Eye
And Vision Research
AEVR



NAEVR
National Alliance For
Eye And Vision Research

Why Funding Vision Research is Vital

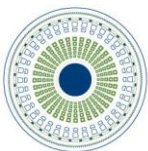
- NEI's FY2019 enacted budget of \$797 M is just 0.5% of the \$167 Billion annual cost to the U.S. of vision disorders, which is expected to grow to \$717 Billion by 2050. **[Messaging around delaying or preventing these costs through vision research investment.]**
- The US is spending \$2.40 per-person in FY2019 on vision research, while the cost of treating low vision/blindness is \$6,680 per-person, per-year.
- Direct medical costs of vision disorders are 5th highest, only less than heart disease, cancers, emotional disorders, pulmonary disorders.
- A 2014 AEVR/Research!America public opinion poll published August 2016 in *JAMA OPHTHALMOLOGY* found that Americans across all racial/ethnic lines identify vision loss as having greatest impact on their life. **[Among top five evergreen citations].**
- A September 2016 National Academies of Sciences, Engineering and Medicine (NASEM) Report issued nine recommendations to eliminate correctable and avoidable vision impairments in the US by year 2030—four requiring federal government action.



Example: NASEM Study on Vision Loss Prevention

Vision Meets with US Surgeon General to Discuss NASEM Report Recommendations

- Met June 13 under auspices of VISION 2020 USA with Surgeon General Jerome Adams, MD, MPH and Deputy Surgeon General Erica Schwartz, MD, JD, to discuss a Call to Action for vision and eye health in the United States, per recommendations that resulted from the 2016 National Academies of Sciences, Engineering and Medicine (NASEM) Report *Making Eye Health a Population Health Imperative: Vision for Tomorrow*.
- Of the report's nine recommendations for a national strategy to eliminate correctable and avoidable vision impairments in the US by the year 2030, four were federal:
 - DHHS Secretary Call to Action
 - DHHS Secretary leads Public Awareness Campaign
 - CDC develops a Coordinated Surveillance System
 - DHHS Secretary creates an Interagency Workgroup
- Study sponsors in attendance included: American Academy of Ophthalmology, American Optometric Association, Prevent Blindness, Lighthouse Guild, and NAEVR, along with federal sponsors CDC and NEI.



Alliance For Eye
And Vision Research
AEVR



NAEVR
National Alliance For
Eye And Vision Research

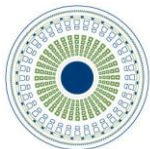
“Vision Should Not be Siloed”



From left: United States Surgeon General Jerome Adams, MD, MPH and Deputy Surgeon General Erica Schwartz, MD, JD

“Vision shouldn’t be siloed. It should integrate within federal public health programs due to the chronic nature of several major eye diseases, as well as vision’s relationship to other chronic diseases, including cardiovascular disease and Alzheimer’s, as well as to visual implications of treatments for those conditions.”

-- June 13 comments by U.S. Surgeon General Jerome Adams, MD, MPH, in meeting with vision community organization and federal agency representatives regarding the National Academies of Sciences, Engineering, and Medicine’s (NASEM) 2016 Report *Making Eye Health a Population Health Imperative*



Alliance For Eye
And Vision Research
AEVR



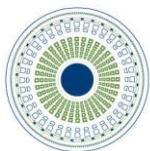
NAEVR
National Alliance For
Eye And Vision Research

Private Vision Research Advocacy: Eye Bonds

Vision Support for “Eye Bonds” Legislation to Leverage Private Equity to Fund Translational Eye and Vision Research:

H.R. 2620 Faster Cures and Treatments for Diseases Act

- Introduced in House on May 9 by six co-sponsors [Sanford Bishop (D-GA), Cathy McMorris Rodgers (R-WA) Steve Cohen (D-TN), Tom O’Halloran (D-AZ), Brad Schneider (D-IL), and Gus Bilirakis (R-FL)].
- A four-year Pilot Program, with private funding through Eye Bonds up to a total of \$1 B, for translational vision research – to bridge the “Valley of Death” from bench to bedside—to accelerate cures and treatments.
- The private funding (from pension plans, insurance companies, etc) would have a federal guarantee, but the Congressional Budget Office (CBO) has determined that the risk is low.
- The National Eye Institute would be involved in identifying potential translational research projects that would benefit from Eye Bond funding.



Alliance For Eye
And Vision Research
AEVR



NAEVR
National Alliance For
Eye And Vision Research