

Advocacy Handbook

Educating key stakeholders about
eye and vision research funding

Second edition





Advocacy Handbook

Contents

Preamble: Using this handbook 3

Introduction: An invitation to advocacy 5

Developing your advocacy plan: Who, what, when and how? 7

 Who is your audience? 7

 What is your message..... 9

 When should you advocate? 10

 How will you disseminate your message? 11

Advocacy in action: Conducting an advocacy visit 13

Advocate tools 15

Please visit [ARVO.org/Advocacy](https://www.arvo.org/Advocacy) for PDF copies of this handbook and related materials.

Acknowledgements

James Jorkasky, Executive Director of National Alliance for Eye and Vision Research/
Alliance for Eye and Vision Research (NAEVR/AEVR)

David Epstein, Director, Government Relations and Education, NAEVR/AEVR

Erin Hering, Manager, Science Communications and Advocacy, The Association for
Research in Vision and Ophthalmology (ARVO)

Julene Joy, Chief Communications Officer, ARVO

Peter Koulen, PhD, FARVO, Chair of ARVO's Advocacy and Outreach Committee

Elliott Sohn, MD, Member of ARVO's Advocacy and Outreach Committee

Van C. Lansingh, MD, PhD, FICO, Member of ARVO's Advocacy and Outreach Committee

Jovi Wong, BSc (Hons), MSc, MD, Dphil, Member of ARVO's Advocacy and Outreach
Committee

Layout and design by John Saville, ARVO

Preamble

Using this handbook

Advocacy is one way to influence a decision that is favorable to you. For the Association of Research in Vision and Ophthalmology (ARVO) members, advocacy is used primarily to educate policymakers and increase eye and vision research funding.

In the United States (US), ARVO engages in many advocacy activities hosted by National Alliance for Eye and Vision Research (NAEVR) to improve awareness of eye disease and vision impairment, and to increase related research funding. ARVO offers this handbook to membership to help you do the same worldwide. This publication presents potential advocacy considerations, activities and examples. This information is presented to help you establish or expand eye and vision research advocacy activities in your home country or region, whether as an individual effort or through collaboration with fellow research or vision-related education or patient organizations.

ARVO is aware of and sensitive to the vast cultural differences among membership, especially as it relates to political systems and ways to communicate. The guidance in this handbook may provide a basis to develop activities that best influence research funding within your home country or region.

Considerations:

- At its core, advocacy is educational. This publication's examples can be used to establish or expand programs that focus on the value of eye and vision research, even if they are not used specifically to influence funding decisions.
- Advocacy programs can influence decision makers in public, private and international funding organizations.
- 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 research.
- Before you engage in advocacy, you should clarify whether this activity is permitted within your terms of employment, especially if you are affiliated with a publicly funded academic institution or serve as a government advisor. This is also the time to determine whether your organization or institution has a dedicated advocacy professional or lobbyist with whom you can collaborate.
- If you are part of a group of researchers forming a national or regional organization devoted to research advocacy, you should understand and comply with government regulations, especially if monetary contributions are solicited.

Preparation

Preparation is key to effective education and advocacy. This document will walk you through considerations and components of developing a quality advocacy message (on page 7), including:

- Who is your audience?
- What is your mission?
- What is your goal?
- When should you advocate?
- How will you disseminate your messages?

ARVO Staff can provide helpful insight and tips for your advocacy event. Email outreach@arvo.org to be connected with the Manager of Science Communications and Advocacy.



Glossary and definitions

- Vision research implies eye and vision research
- Eye disease implies vision impairment and eye disease
- Press – a variety of written, visual, audio, and electronic media
- NEI – National Eye Institute within the US National Institutes of Health (NIH)
- Coalition partners – organizations with whom you can work collaboratively to disseminate your advocacy message. These may include educational foundations and organizations, patient organizations and may be dedicated solely to vision issues or comorbidities. Member organizations of the National Alliance for Eye and Vision Research (NAEVR) and the Alliance for Eye and Vision Research (AEVR)—of which ARVO is a founding member—may be a good place to start.

Introduction

An invitation to advocacy

Advocacy for vision research funding can

- be conducted as a formal or informal effort
- be conducted as a one-on-one effort
- be conducted as a group effort
- engage fellow researchers or other organizations interested in vision health issues or comorbidity issues, e.g. aging, diabetes, social determinants of health
- focus on garnering support from national or regional public or private entities
- focus on garnering support from international public or private entities
- encompass a wide range of communication tactics and channels

Why advocate for vision research funding?

Improve understanding – increase education and awareness

- There is still significant incidence of eye disease, as indicated by current and projected statistics based on an aging population, increasing diversity, nutrition and lifestyles, environmental conditions and economy/workplace conditions.
- There are economic and social burdens of eye disease, expressed as direct and indirect healthcare costs, workforce productivity, quality of life and regional and global competitiveness.
- Vision needs are still unmet, as demonstrated by inadequacy of nation's vision health care and social services systems, the research pipeline, rehabilitation usage, qualities of life.
- Current disease preventions, diagnoses, treatments and rehabilitations are leading the way.

Encourage action – influence government support

- Current government investment in vision research remains largely inadequate when one accounts for funding for:
 - Assessment of national vision health and subsequent impact on the economy
 - Basic translational vision research
 - Vision prevention, diagnosis, treatment and rehabilitation programs
 - Access to vision care, both in public and private care settings
- Governments need to invest in adequate research/vision care infrastructure
- Identifying vision priorities is the first step



- Vision research is cost-effective
 - Vision research can delay, save or prevent direct and indirect healthcare expenditures and improve quality of life, making it an excellent return-on-investment (ROI)
- Foster collaboration – expand sphere of influence
 - A well-designed effort can bring focus and credibility to an issue domestically and internationally, thereby expanding the sphere of influence and potentially engaging other organizations

Developing your advocacy plan

Who, what, when, how?

Who is your audience?

Who are you attempting to influence? Your answer may be more than one of the options listed below, so consider which are primary and which are secondary priorities. For any audience, there are several considerations you will need to clarify.

Public funding sources

- Legislators/policymakers
 - Do you have access to the legislators or their staff?
 - How is the national budget developed?
 - How are research budget decisions made?
 - Are there dedicated committees and staff that develop budget and spending recommendations?
 - How can the public provide input in that process, formally and/or informally?
 - What are the deadlines and filing requirements for making a budget request? What is the required format and content of these requests?
- Executive branch officials/ministries
 - How do executive branch officials and ministries influence budget and spending decisions, if at all? Do they merely implement programs?
 - Are there defense programs related to vision (e.g., US Department of Defense and Department of Veterans Affairs Vision Center of Excellence)?
- Government health or research agency, government regulators/payers
 - What degree or influence and discretion do individuals at these agencies have? Do they merely implement programs?
 - Can research out of agencies impact policy?
 - Can well-developed incidence and economic burden data assist these agencies in understanding vision research's ROI?
- Academic institutions
 - Is research funding prioritized and managed at a centralized or decentralized level?
 - How collaborative is the institution's vision research with other key research areas?
- Regional governments/International alliances public funding sources

Example: The European Union (EU) funds health and social programs broadly. It provides funding for programs for aging populations, consider an advocacy message about the impact of aging on vision.

Advocacy Tip

Check out ARVO's
International
Advocacy Toolkits



■ International public funding sources

Examples: World Health Organization (WHO), UNICEF
 Questions presented under “public funding sources” also apply here.

Private funding sources

■ National

Examples: academic institutions, philanthropic foundations, patient advocacy organizations

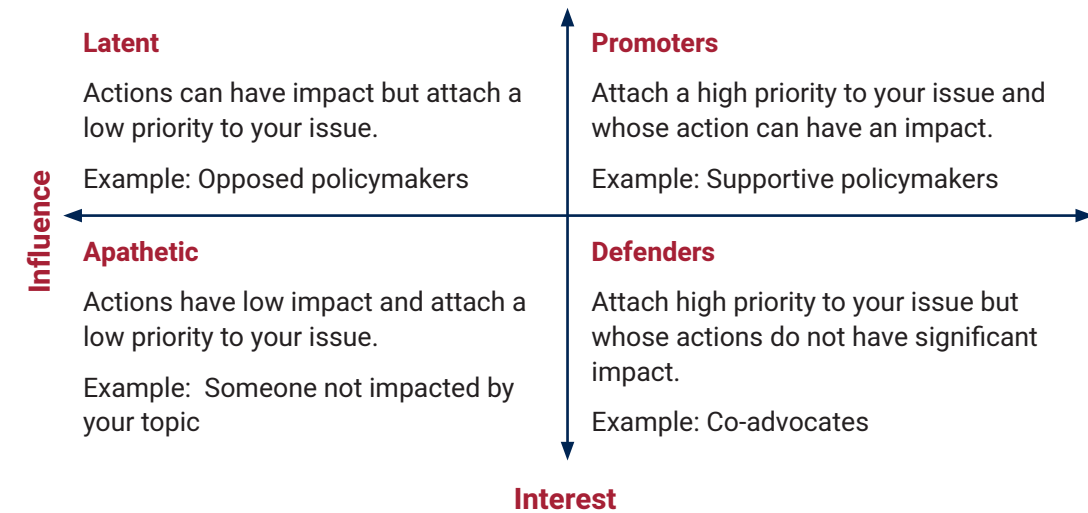
■ International

Examples: philanthropic foundations, patient advocacy organizations

■ Corporate

Corporate funding and partnerships can be important for developing both educational and advocacy programs that can range from evaluating the incidence of eye disease to the 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

Consider influence vs. interest



What is your message?

A comprehensive advocacy message contains the following components.

	Component	Outline
1	Request – Simple and clearly stated	Main ask
2	Issue – Broadly, what are you talking about?	Impact on <ul style="list-style-type: none"> ■ Patients ■ Regions ■ Key populations
3	Problem – Specifically, what are you concerned about?	Data on <ul style="list-style-type: none"> ■ Disease prevalence ■ Disease burden ■ Economic burden ■ Societal burden
4	Findings/Solutions – Additionally details about what you’re asking for.	<ul style="list-style-type: none"> ■ Promising advances ■ Inadequacies and missed opportunities ■ Current funding ■ Funding needed
5	Benefits – How will this impact society?	<ul style="list-style-type: none"> ■ Patient-level ■ Community levels <ul style="list-style-type: none"> ● Regionally ● Nationally ● Key populations
6	Request – Restate	Reiterate the main ask

Advocacy Tip
 Interested in science communication? Consider applying for ARVO’s Science Communication Training Fellowship.

When appropriate, tailor and target your message based on your understanding of your audiences’

- Personal experience with vision loss.
- Home country, region or district – Be able to describe the research being conducted at institutions in your audiences’ home country, region or district.
- Educational experience – Understand through which lens(es) your audience is digesting your message based on their degree(s), volunteer work, societies, and professional career.
- Affiliation and stance on key issues – Understand your audiences’ political affiliation and how it relates to your request.

If possible, obtaining patient testimonials can be outstanding additions to your advocacy messaging. A patient’s testimonial can be very influential, whether presented in person, on video, or in written testimony. Ask patients to describe the impact of eye disease in their lives and how research could potentially save or restore their vision and/or improve their quality of life. Be prepared to supplement patient testimonials with facts and figures from your message to support your request.





When should you advocate?

Advocating is a year-round activity, but there are certainly opportunities within your country's funding cycle that you can capitalize on.

- What is the budget cycle? – Is it annual, biannual, etc.?
- What are the steps in the budget cycle?
 - Do various departments or agencies develop funding recommendations which are then presented to a legislative or executive body? If so, are there opportunities—public or private— including venues, portals for public comment or testimony to influence these recommendations?
- Is there an appropriate national health observance (NHO) with which to align? There are various national health observances, and some may be international efforts. Aligning your advocacy with these observances will inevitably “boost” your message. Some U.S. eye- and vision-related examples include:
 - **January** – National Glaucoma Awareness Month, National Drug and Alcohol Facts Week
 - **February** – Low Vision Awareness Month, African Heritage & Health Week, World Cancer Day, National Donor Day
 - **March** – Save Your Vision Month, Brain Awareness Week, American Diabetes Alert Day
 - **April** – National Minority Health Month, Sports Eye Safety Awareness Month, Women's Eye Health and Safety Month, National Public Health Week, World Health Day
 - **May** – Healthy Vision Month, National Women's Health Week
 - **June** – Cataract Awareness Month, Fireworks Eye Safety and Cataract Awareness Month, Men's Health Month, Men's Health Week
 - **July** – UV Safety Month
 - **August** – Children's Eye Health and Safety Month, Contact Lens Health Week
 - **September** – Healthy Aging Month
 - **October** – Eye Injury Prevention Month, Home Eye Safety Month
 - **November** – American Diabetes Month, Diabetic Eye Disease Awareness Month
 - **December** – Safe Toys and Celebrations Month

How will you disseminate your messages?

Once you've developed your message and determined timing, you'll need to select channels through which to disseminate your message. Your channels or tactic can be in-person or from a distance, depending on feasibility, and a robust advocacy campaign usually consists of both.

In person	From afar
<ul style="list-style-type: none"> ■ Present an educational session ■ Visit a governmental official ■ Host a governmental official at your institution ■ Host/attend an advocacy day 	<ul style="list-style-type: none"> ■ Write a letter ■ Present a testimony ■ Distribute a press release ■ Develop a graphic ■ Develop a factsheet ■ Engage on social media ■ Write an article ■ Launch a website ■ Host a webinar ■ Schedule a video call

Set a goal and capture metrics so that you can determine whether your advocacy was successful. Success metrics will vary depending on which channel(s) you use, but can be quantitative or qualitative, and may include:

- Registration
- Attendance
- Feedback survey
- Press pickup
- Factsheet downloads
- Social media engagement
- Website page visits/views



Advocacy in Action

Conducting an advocacy visit

Set an achievable goal

See page 5.

Establish context

Are you introducing an issue or following up on a previous conversation? Since it may take one meeting to iterate the request and messages, you may have multiple interactions.

What is the context of your visit? Are you requesting funding on behalf of yourself, institution, home country, etc.

Are you committed to following through? Are you willing to respond to questions, serve as a resource for vision-related questions, be available for regular communications?

Request a visit

- **Who are you visiting and why are they important?** This will help you determine the messages and tone you use.
- **What is the best way to communicate with this person?** Evaluate what the best channel or tactic to reach this person (in person vs. from afar).
- **Who are you representing?** Are you representing yourself, your institution, your research community or a combination? As appropriate, note any special role you hold in the institution or organization.
- **What is the purpose of your visit?**
- **What is the appropriate message?**
- **What questions and challenges may you encounter?** Policymakers may want to know more about an issue, especially how it impacts the people, programs and policies they oversee. During a budget cycle, they may want to discuss the implications of your funding request.

Conduct a 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.

Sample Visit Request

Use this email template adapted from Federation of American Societies For Experimental Biology (FASEB) to request an office visit.

Dear Representative/Senator _____:
I am writing to request an appointment with you and/or members of your staff on [date and time] in your [Washington, D.C. or district office]. I wish to discuss eye and vision research funding and how it impacts [your state or district].

Thank you in advance for your consideration of this request. Please contact me at [your email address] or [phone number] to schedule a meeting time. If you are not the appropriate contact for this request, kindly refer me to the appropriate staff person so that I may reach out directly.

Sincerely,

[Your name, institutional affiliation, and contact information with mailing address and email]

Advocacy Tip
Email
outreach@arvo.org
to be connected
with the Manager
of Science
Communications
and Advocacy
who can review
your factsheet
for clarity.

Advocacy Tip
Many policymakers have a social media presence. In addition to a formal letter, thank the policymaker via social media by tagging them and restating the purpose of your visit.

- 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 the 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).

Follow-up

Post-meeting communication with the recipient of your advocacy message is important. It allows you to once again reiterate your request and to put it in a context that may 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.

Does this make me a lobbyist?

Every U.S. citizen has the right to communicate with their elected representatives. However, if you work at an institution supported by federal or state funds, do not conduct your communications with Congress using your office computer or telephone.

For more information, contact your institution's government relations office.

Advocate tools

- National Alliance for Eye and Vision Research/Alliance for Eye and Vision Research
- ARVO's International Advocacy Toolkits
- ARVO Advocacy Updates
- Optical Illusions
- Capitol Hill Day Handbook
- National Eye Institute, National Institutes of Health funding
- Vision and Blindness factsheet
- NEI accomplishments



The Association for Research
in Vision and Ophthalmology

5515 Security Lane, Suite 500
Rockville, MD 20852
+1.240.221.2900 (tel)
+1.240.221.0370 (fax)

ARVO.org

Second edition: Dec., 2020