

ARVO International Advocacy Toolkit: United States (U.S.)

1. Which organization(s) are significant sources of research funding? (e.g., national/local governments; private funding/foundations/charity groups; large non-governmental organizations (NGOs); industry/pharmaceutical companies)

National Government

- [National Institutes of Health](#) – [National Eye Institute \(NEI\)](#), [National Institute of Aging \(NIA\)](#), [National Institute of Neurological Disorders and Stroke \(NINDS\)](#) and others may be relevant to vision/ophthalmic research investigators.
- [Veterans Affairs \(VA\)](#)
- [Department of Defense \(DOD\)](#)
- [National Science Foundation \(NSF\)](#)
- [Fulbright Commissions](#) (travel for scholarship)

Local/Regional Governments

- Local governments also offer grants in various Regional Ministries, including Education, Health and Industry.
- [Lions Eye Bank of Wisconsin \(LEBW\)](#)
- [University of Wisconsin McPherson Eye Research Foundation](#)
- [Lions International and Rotary International](#) (Local Chapters)

Private Foundations

- [The Hartwell Foundation](#)
- [Knights Templar Eye Foundation](#)
- [Research to Prevent Blindness \(RPB\)](#)
- [Retina Research Foundation \(RFF\)](#)
- [Foundation Fighting Blindness \(FFB\)](#)
- [Fight for Sight](#)
- [The Glaucoma Foundation](#)
- [Glaucoma Research Foundation](#)
- [The Marfan Foundation](#)
- [ARVO Foundation for Eye Research](#)
- [American Macular Degeneration Foundation \(AMDF\)](#)

Industry/Pharmaceutical companies

- Many pharmaceutical companies and biotech start-ups.

Non-governmental Organizations (NGOs) and Charities

- [BrightFocus Foundation](#) (included here as international in scope)
- [International Agency for the Prevention of Blindness \(IAPB, for advocacy\)](#)
- [International Council of Ophthalmology \(ICO\)](#)

2. What does the normal science funding/policy decision-making process look like?

What are the criteria the funding/policy organization(s) use to make their decisions?

Likely impact on improvements to patient health outcomes, alignment with strategic priorities of the organization and availability of funds. Some organizations will look at the likelihood of securing larger grants in the future from other agencies whereas some organizations look for high-risk/high-reward proposals.

Which group/committee/person within the funding/policy organization makes the decisions?

Ultimately, federal budget appropriations available for funding research are determined at the Congressional level. NIH agencies frequently engage expert panels to help determine strategic priorities, with influence from institute directors.

3. Which patient advocacy groups, if any, are active in the area?**National**

- [Glaucoma Research Foundation](#)
- [Marfan Foundation](#)
- [Alliance for Eye and Vision Research \(AEVR\)](#)
- Numerous disease-specific groups e.g. [Macular Degeneration Foundation](#)

4. Are there existing national/regional organizations that work towards improving research funding/policy?

- [National Alliance for Eye and Vision Research \(NAEVR\)](#)
- [Lions International](#)

5. How do scientists currently contribute to the existing funding/policymaking/advocacy process, if at all?

Through responding to calls for information and input e.g. from NIH, attending NEI workshops, through direct engagement in advocacy e.g. NAEVR or on behalf of disease-specific patient groups or professional organizations (e.g. ARVO and the American Academy of Ophthalmology (AAO) Advocacy Days) with legislators and with policymakers.

6. When are science funding/policy decisions made?

During the governmental budget appropriations process and in NIH Council meetings.

7. What kinds of opportunities exist for scientists to interact with funders and policymakers?

Can scientists invite decision makers to their lab/institution to see their work firsthand?

This can be useful and appropriate when reaching out to philanthropists and private foundations, but care needs to be taken in engaging with policymakers/decision makers/grant reviewers to ensure that it's not seen as an attempt to subvert the process.

Do the funding/policy organizations hold open meetings or solicit comments from the public that researchers can participate in?

Yes, comments are solicited and less frequently, workshops and open meetings are held that individual researchers can participate in.

Contributors:

Gillian J. McLellan, BVMS, PhD, University of Wisconsin-Madison