

ARVO International Advocacy Toolkit: Ireland

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:

Several state and semi-state organizations exist in Ireland that invest in basic, translational, and clinical ophthalmology research. Many of these funding bodies also prioritize vision research that is close to commercialization.

Science Foundation Ireland (SFI) is an Irish statutory body which provides funding for orientated basic and applied research across the areas of science, technology, engineering and mathematics. <http://www.sfi.ie/funding/>

Enterprise Ireland (EI) is a government body which provides support to businesses, including early start-up innovations. <https://enterprise-ireland.com/en/funding-supports/>

Health Research Board (HRB) is a statutory agency under the aegis of the Department of Health which provides funding and oversight for health research, information and evidence in Ireland. <http://research.ie/funding/>
In addition, the Department of Health invests in the development of medical research in Ireland through a co-funding scheme between the HRB and Medical Research Charities Groups (MRCG). <http://www.hrb.ie/research-strategy-funding/open-grants-and-fellowships/mrcghrb/>

Irish Research Council (IRC) is an independent and autonomous research funding and monitoring body with a mission to enable and sustain a vibrant research community in Ireland by supporting excellent researchers across all disciplines and career stages. Collaborative funding opportunities exists which enable host Institutions to partner with a business, a company, a registered charity, a not-for-profit civic organization or semi-state commercial organization. <http://research.ie/funding/>

Private Foundations:

The Wellcome Trust is a UK-based research organization which also offers support (including financial) to Irish biomedical research. The Wellcome Trust identifies priority research areas and have funded many retinal gene therapy trials. <https://wellcome.ac.uk/funding>

Industry/pharmaceutical companies:

In recent years, Ireland has become one of the leading and most attractive locations in the world for the pharmaceutical industry. As such, an increasing number of industry and

biotechnologies are now investing in ophthalmology research in Ireland, particularly in common retinal disease such as age-related macular degeneration (AMD) and diabetic retinopathy. In parallel to supporting ophthalmologic research and the development of therapeutic indications, larger pharmaceutical companies are also investing in real world evidence research.

Non-governmental Organizations (NGOs) and Charities:

Fighting Blindness Ireland is a medical research charity invests in research that holds the potential to result in a therapeutic intervention for sight loss. It funds across the full life cycle of research i.e. basic, translational, and clinical. It also invests in population research in terms of identifying the economic costs and impact on quality of life associated with retinal disease. Fighting Blindness Ireland recently launched a survey to identify the research priorities of those living with sight loss. The results from this will also greatly guide the decision process for Fighting Blindness.

<https://www.fightingblindness.ie/>

European Funding Opportunities in Ireland:

European Reference Networks (ERN-EYE) aims to provide the best care to patients with rare eye disease across the EU, improving diagnostic tools, harmonising clinical and pre-clinical research and bringing best practices and training for rare eye diseases. It involves four thematic working groups: rare diseases of the retina, neuro-ophthalmology rare diseases, paediatric ophthalmology rare diseases, and rare anterior segment conditions and six transversal working groups. Research, innovation and knowledge generation are key elements of the ERN EYE. <https://www.ern-eye.eu/>

Horizon 2020 is the biggest EU Research and Innovation programme which aims to ensure Europe produces world-class science, removes barriers to innovation and makes it easier for the public and private sectors to work together in delivering innovation.

<https://ec.europa.eu/programmes/horizon2020/>

European Research Council (ERC) is a public body for funding of scientific and technological research conducted within the European Union (EU). Researchers from any field can compete for the grants that support pioneering projects.

<https://erc.europa.eu/>

The Marie Skłodowska-Curie Actions (MSCA) provide grants for all stages of researchers' careers, be they doctoral candidates or highly experienced researchers, and encourages transnational, intersectoral and interdisciplinary mobility. Types of MSCA opportunities include:

- **Innovative Training Networks (ITN)** aims to train a new generation of creative, entrepreneurial and innovative early-stage researchers (typically PhD and Masters' degree students). ITN aims to provide excellence and structure research and doctoral training and equipping researchers with the right combination of research-related and transferable competences.

- **Individual fellowships (IF):** support the mobility of researchers within and beyond Europe - as well as helping to attract the best foreign researchers to work in the EU.
- **International and inter-sectoral cooperation through the Research and Innovation Staff Exchanges (RISE)** supports short-term mobility of research and innovation staff at all career levels, from the most junior (post-graduate) to the most senior (management), including administrative and technical staff.
- **COFUND** aims at co-financing high-quality fellowship or doctoral programmes with transnational mobility. The fellowship covers a researcher unit cost (amount depending on the researcher - early stage or experienced), and an institutional unit cost.
<https://euraxess.ec.europa.eu/jobs/funding/marie-sklodowska-curie-actions-cofund>

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

Each organization investing in ophthalmology-based research will have their own policies and pathways for funding approval. For the majority, the process is generally initiated through a call on an annual or multi-annual basis. Organizations typically seek competitive, collaborative research projects to address the theme of call. The type of activity expected is also covered in the topic description, as is the scope and impact of projects.

Following shortlisting of applications that are best aligned with specific call and the research strategic priorities of the organizations, all projects undergo an international peer review. Peer review is crucial to the decision-making process and is necessary to ensure that projects funded are internationally competitive and of the highest standard. A minimum of 3 peer reviewers, who are experts in the research area proposed, would typically be required. They examine the proposal on the grounds of scientific quality/innovation, expertise and research environment and relevance and impact of the research on the disease areas of the selected organizations/charity each weighted to ensure each proposal is adequately assessed.

There is an increased effort to ensure that applications for funding include meaningful public and patient involvement (PPI). Following a scientific committee review, final approval for funding takes place at an organizational Board level. Further information on the science funding/policy decision-making process for each scheme described above can be found on their organizational website.

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

Fighting Blindness Ireland: is an Irish patient-led charity with a vision to cure blindness, support those experiencing sight loss and empower patients. Fighting Blindness strongly support the efforts being made to advance the area of retinal research through funding retinal research projects and providing platforms for presenting such research at the Retina conference for example. The Board of Directors consists of several patient/patient representatives, advocating on behalf of all people served by the organization to ensure the



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organization supports the highest quality retinal research. For further information on Fighting Blindness funded research, contact research@fightingblindness.ie or visit www.fightingblindness.ie

Retina International: is a charitable umbrella association of 43 national societies that are created and run by people with retinitis pigmentosa, Usher syndrome, macular degeneration and allied retinal dystrophies and their families and friends. Their mission is to facilitate the development of and the global access to proven treatments and cures for retinal dystrophies. For further information please visit www.retina-international.org.

Medical Research Charities Group (MRCG): The MRCG is the national organization of charities active in medical research. MRCG members are significant funders and contributors to the research landscape in Ireland. Their mission is to nurture a vibrant, dynamic, patient-led medical research environment in Ireland. MRCG goals include make case for improved policy, advocating from improved institutions, make case for better outcomes. A core belief of the group is that today's health research is tomorrow's healthcare. www.mrcg.ie

Rare Disease Ireland (RDI): This is a national alliance for voluntary groups which represent people with or at risk of developing genetic or other rare disorders with a goal to improve support and services. www.grdo.ie

Irish Health Research Forum (IHRF): The IHRF is a partnership of organizations and stakeholders that aims to influence health research in Ireland and allows these bodies to work together to enable high quality research, to support research careers and to promote the involvement of service users. The forum considers key health research issues, identifies constructive solutions and seek consensus at twice annual forum meetings of Health Research stakeholders. www.ihrf.ie

The Irish Platform for Patient Organisations, Science and Industry (IPPOSI): is a patient-led organisation that works with patients, government, industry, science and academia to put patients at the heart of health policy and innovation. IPPOSI is the primary contact and conduit for patients interested in engaging more actively in the R&D process. IPPOSI membership is open to anyone with an interest in healthcare and research and development. www.ipposi.ie

Do they partner with researchers to promote research funding and policy?

Yes, there is a strong and collaborative relationship between the research community in Ireland and the various organizations advocating in the field. For example, a recent report published seeks to reflect the views of a wide range of key stakeholders including patient groups, funders, policy makers, academics and industry, with a emphasis on capturing the views of 'frontline' health researchers in Ireland.

www.mrcg.ie/.../MRCG_Research_Report.pdf

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

Scientists can contribute by participating in the peer review process but also by providing insight into the current research funding landscape and allowing organizations advocating on their behalf to make informed and educated recommendations to relevant policy makers.

5. When are science funding/policy decisions made?

All funding bodies identified make funding decisions annually on a set schedule. Typically, the call will include a time schedule which sets out when calls are open/closed, when proposals are under review and when decisions are being made.

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

Many opportunities exist for scientists to interact with funders and policymakers. One example, is the annual retina conference organised by Fighting Blindness which brings together all stakeholders including scientists, clinicians, regulators, industry, funders etc.

[Can scientists invite decision makers to their lab/institution to see their work firsthand?](#)

It is also quite common for scientists to invite decision-makers to the research site and view the infrastructure and skills available. Opportunities also exist for scientists to provide feedback and suggestions regarding the application and evaluation process.

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

Following a call for research, funders would often host information events such as breakfast briefings, webinars or workshops to provide guidance to interested scientists. In addition, all funders have a very interactive social media platform, regular newsletters to promote opportunities across all institutions and interested parties.

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

As previously described, funding/policy organizations often seek feedback from the public and researchers as a means of advancing the research landscape to best suit the needs of all relevant stakeholders. Recently, the HRB launched a survey in to investigate researcher and public perception towards Public and Patient Involvement in Research (PPI) in Ireland. They also called for public reviewers on grant applications. This was the first attempt of an Irish research funder to incorporate a joint public and scientific review of research applications. This style of review is becoming increasingly favored and will become more evident in calls to come.

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