

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 in Ireland invest in basic, translational and clinical ophthalmology research. Many of these funding bodies also prioritize vision research close to commercialization.

- [Science Foundation Ireland \(SFI\)](#) is an Irish statutory body that provides funding for orientated basic and applied research across science, technology, engineering and mathematics. It is the largest funder of competitive research.
- [Enterprise Ireland \(EI\)](#) is a government body supporting Irish-owned businesses, including early start-up innovations.
- [The Health Research Board \(HRB\)](#) is a statutory agency under the aegis of the Department of Health that provides funding and oversight for health research, information and evidence in Ireland. In addition, the Department of Health invests in medical research development in Ireland through a co-funding scheme between the HRB and [Health Research Charities Ireland \(HRCI\)](#).
- [The 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 exist to help host institutions partner with a business, a company, a registered charity, a not-for-profit civic organization or a semi-state commercial organization.

Private Foundations

[The Wellcome Trust](#) is a UK-based research organization that offers support (including financial) to Irish biomedical research. The Wellcome Trust identifies priority research areas and has funded many retinal gene therapy trials.

Industry/Pharmaceutical companies

In recent years, Ireland has emerged as one of the world's most attractive and leading locations for the pharmaceutical industry. Thus, an increasing number of industries and biotechnologies are investing in ophthalmology research in Ireland, particularly in common retinal diseases 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 that invests in research that holds potential results in therapeutic intervention for sight loss, with a particular focus on the wide spectrum of retinal degenerative diseases. 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 the quality of life associated with retinal disease. Fighting Blindness Ireland previously launched a survey which identified the priorities of those living with sight loss. The feedback informed the direction and goals of the charity's research strategy.

[Breakthrough Cancer Research](#) is a medical research charity that invests in cancer research, particularly in the areas of cancer prevention, diagnosis and the development of new treatments. It funds translational research. As part of their "Strategic Plan 2023–2026", they aim to invest 3.25M annually. They have funded uveal melanoma projects, especially ones that investigate novel pathways and treatment targets.

[The National University of Ireland \(NUI\)](#) awards the NUI traveling doctoral studentships to encourage students to pursue research in science and engineering.

European Funding Opportunities in Ireland

[European Reference Networks \(ERN-EYE\)](#) aims to provide the best care to patients with rare eye diseases across the European Union (EU), improving diagnostic tools, harmonizing 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, pediatric ophthalmology rare diseases and rare anterior segment conditions. It also involves six transversal working groups. Research, innovation and knowledge generation are key elements of the ERN EYE.

[Horizon Europe](#) is the biggest EU research and innovation program that 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.

[The European Research Council \(ERC\)](#) is a public body funding scientific and technological research in the European Union (EU). Researchers from any field can compete for grants that support pioneering projects. There are four core grant schemes: Starting Grants, Consolidator Grants, Advanced Grants and Synergy Grants.

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

- **Doctoral Networks (DN)**: DN's objective is to implement doctoral programs through partnerships with organizations from different sectors across Europe and beyond to train highly skilled doctoral candidates, stimulate their creativity, enhance their innovation capacities and boost their employability in the long term.
- **Postdoctoral Fellowships (PF)**: PF's objective is to support researchers' careers and foster excellence in research. The Postdoctoral Fellowships action targets researchers with a PhD who wish to conduct their research activities abroad, acquire new skills and develop their careers. PFs help researchers gain experience in other countries, disciplines and non-academic sectors.
- **International and inter-sectoral cooperation through Staff Exchanges (SE)**: The Staff Exchanges action funds short-term international and inter-sectoral exchanges of staff members involved in research and innovation activities of participating organizations. The aim is to develop sustainable collaborative projects between various organizations from the academic and non-academic sectors, particularly SMEs, based in Europe and beyond. Exchanges' staff benefit from new knowledge, skills and career development perspectives while participating organizations increase their research and innovation capacities.
- **COFUND**: COFUND aims at co-financing high-quality fellowship or doctoral programs with transnational mobility. The fellowship covers a researcher unit cost (amount depending on the researcher - early stage or experienced), and an institutional unit cost.

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

Each organization investing in ophthalmology-based research will have its policies and pathways for funding approval. The process is generally initiated through an annual or multi-annual call. Organizations typically seek competitive, collaborative research projects to address the theme of the call. Also, the expected activity type should be included in the topic description, as is the scope and impact of projects.

Following the shortlisting of applications aligned with a 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 three peer reviewers, 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 funding applications include meaningful public and patient involvement and engagement (PPIE). Patients and members of the public are becoming more involved in the review process. 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: An Irish patient-led charity with a vision to cure blindness, support those affected by sight loss and empower patients. Fighting Blindness Ireland strongly supports 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 annual 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 organization supports the highest quality retinal research. For further information on Fighting Blindness-funded research, contact research@fightingblindness.ie.

Retina International: A global charitable umbrella association of 43 national societies created and run by people with conditions including retinitis pigmentosa, usher syndrome, macular degeneration and allied retinal dystrophies and their families and friends. Their mission is to facilitate the development of global access to proven treatments and cures for rare, inherited, or age-related retinal dystrophies.

Health Research Charities Ireland (HRCI): The HRCI is the national umbrella organization of charities active in health and medical research. HRCI charity members are significant funders and contributors to the research landscape in Ireland. Their mission is to nurture a vibrant and dynamic patient-led medical research environment in Ireland. HRCI's goals include making a case for improved policy, advocating for improvement in institutions and making a case for better outcomes. HRCI also runs the Irish Health Research Forum, bringing together various stakeholders to positively impact health

research in Ireland. A core belief of the group is that today's health research is tomorrow's healthcare.

[Rare Disease Ireland \(RDI\)](#): A national alliance for voluntary groups representing people with or at risk of developing genetic or other rare disorders to improve support and services.

[The 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, support research careers and promote the involvement of service users. The forum considers key health research issues, identifies constructive solutions and seeks consensus at twice-annual forum meetings of health research stakeholders.

[The Irish Platform for Patient Organisations, Science and Industry \(IPPOSI\)](#): A patient-led organization 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 interested in healthcare and research and development.

[The Public and Patient Involvement \(PPI\) Ignite Network](#): The Network promotes excellence and innovation in PPI in health and social care research. The Health Research Board (HRB) and the Irish Research Council (IRC) fund the PPI Ignite Network, with co-funding from lead universities.

[The Patient Voice in Cancer Research](#): A national initiative led by the University College Dublin to actively engage cancer patients, cancer researchers and those interested in cancer research (patient advocates, families, carers, healthcare professionals, polymakers) in discussion and decision-making processes that positively impact on cancer research and outcomes for patients.

[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, an Irish Health Research Forum (IHRF) report published previously highlighted the outcomes of a multi-stakeholder event composed of patient advocacy groups, funders, policymakers,

clinicians, academics and industry. This event facilitated in-depth discussions addressing the need for supporting and embedding research into health services.

[Health Research Charities Ireland \(HRCI\)](#) also promotes the progression of health research by supporting partnerships between HRCI member charities and researchers. HRCI, partnering with the [PPI Ignite Network](#), recently published a guide to support the establishment of effective partnerships between researchers and charity/advocacy groups to enhance the impact of health research.

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, offering insights into the current research funding landscape and allowing advocacy organizations to make informed and educated recommendations to relevant policymakers.

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 schedule that sets out when calls are open/closed, when proposals are being reviewed 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 organized by Fighting Blindness which brings together all stakeholders including scientists, clinicians, regulators, industry, funders, etc.

The Department of Health has launched a pilot open research call under the new [‘Evidence-for-Policy’ \(EfP\) Research Programme](#). The EfP Research Programme is a new funding call co-designed by the Department of Health and the HRB to harness academic research supporting policy decision-making.

There are also opportunities at the EU level, such as a new initiative to enhance research impact and strengthen connections with EU policies. Under [the Marie Skłodowska-Curie Actions \(MSCA\) Feedback to Policy call the European Commission](#) will award up to €2 million to map and assess thematic links between MSCA projects and their contribution to several EU policy priorities. It will also collect feedback from the MSCA research and innovation community on strategies to maximize the program's impact.

[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 often host information events such as breakfast briefings, webinars or workshops to guide interested scientists. In addition, all funders have a very interactive social media platform and regular newsletters to promote opportunities across all institutions and interested parties. As previously described, funding/policy organizations often seek feedback from the public and researchers to advance the research landscape to best suit the needs of all relevant stakeholders. Recently, the HRB launched a survey to investigate researchers' and public perceptions towards PPI in research. 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 review style is becoming increasingly favored and will become more evident in future calls.

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