Health Research Charities Ireland

HRCI
Annual Report
2025

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Contents

A message from the Chairperson and CEO 4

About HRCI and our members 6

- HRCI vision and values 6
- Our Strategic aims 2024 – 2027 7
- HRCI Member Charities 2025 9
- Member Story: Irish Cancer Society 10
- Achievements and performance 11

Aim 1: Empower HRCI members in their research activities 11

- Facilitating Connection, Collaboration and Research Exchange through HRCI Board and Member Meetings 11
- Mastering Research Impact 12
- Shaping Meaningful Research– partnering with Maynooth University 13

Aim 2: Facilitate excellent research through the HRCI-HRB Joint Funding Scheme 14

- Strengthening the Joint Funding Scheme 14
- Guidance and Support for Participating Charities 14

Aim 3: Strengthen PPI and the involvement of our members in health research 16

- Strengthening Member Capacity through the Shared Learning Group 16
- Creating inclusive PPI spaces in research 17
- From Voices to Action: Building Inclusive PPI Together at the UL Summer school 18
- Advancing Public and Patient Involvement in Europe through the European Rare Disease Research Alliance 18
- Partnering for Progress: Our Involvement in the National PPI Ignite Network 19

Aim 4: Positively influence Ireland's health research landscape 20

- HRCI Position Paper 2025: Enhancing health research in Ireland 20
- Advocating for health research 21
- Managing the Irish Health Research Forum - A single voice for health research 22
- A year of the Irish Health Research Forum 23
- Proudly representing our members on a national platform 25
- Advancing Rare Disease Research Through Partnership 26
- Communicating the value of health research 28

HRCI governance 29

- Overview of HRCI Governance: 29
- HRCI Structure 30
- HRCI Board Members 30
- HRCI Board responsibilities 34
- HRCI Subcommittees 36
- HRCI Staff Members 39
- Acknowledgements for Funding 41

Financial Statements 42

- Directors' Report 43
- Directors Responsibilities statement 50
- Independent Auditor's report to the members 51
- Statement of Financial Activities 54
- Balance Sheet 55

A message from the Chairperson and CEO

We are pleased to introduce the HRCI Annual Report for 2025. At a time when trust in expertise and evidence is being tested around the world, it has felt more important than ever to champion the value of research in Ireland and to ensure that it remains connected to the needs and experiences of the people it is intended to serve.

At the heart of HRCI is a belief that research works best when it is shaped by those people and communities. During 2025, we continued to support our members to strengthen public and patient involvement (PPI), build research partnerships and maximise the impact of the research they fund and champion. In return, our members continued to enrich our work through their insights and willingness to collaborate, helping to ensure that our priorities remain grounded in the needs of the communities they represent.

The Irish Health Research Forum continued to provide a trusted space for discussion and problem-solving. Alongside a major Forum event on patient registries, we piloted smaller workshops focused on advocating for health research. What stood out most at these events in Cork and Dublin was the energy and commitment in the room. It was a reminder of the value of bringing people from different backgrounds together around a common goal.

The HRCI-HRB Joint Funding Scheme remains a cornerstone of our activities. During 2025, we supported participating charities through the early stages of a new funding round while also working with the Health Research Board to introduce improvements informed by member feedback and independent evaluation. We welcome the continued enthusiasm for this unique partnership model, which combines scientific excellence with the priorities and perspectives of patients, families and communities.

We also remained active in influencing the wider research landscape through participation in numerous national committees, advisory groups and partnerships spanning clinical research, genomics, mental health, rare diseases and research policy. This involvement helps ensure that the perspectives of charities and the communities they represent inform national decision-making, while also enabling us to stay abreast of emerging national priorities.

Our 2025 Position Paper provided an important focus for engagement with politicians and policymakers. We were encouraged to see our recommendations discussed at political level and reflected in parliamentary questions, helping to raise the profile of health research in policy discussions where it has historically received limited attention.

Behind all of this sits the ongoing work of maintaining a strong, sustainable and well-governed organisation. None of our achievements would be possible without the commitment of our members, Board, staff team, committee members, funders and partners. We extend our sincere thanks to all who contributed to HRCI's work during the year.

There is still much to do, but we remain optimistic about what can be achieved. By combining evidence, expertise and lived experience, we can help ensure that health research continues to improve lives and deliver benefits for society as a whole.

Dr Avril Kennan
CEO, HRCI

Brian Lynch,
HRCI Chairperson

About HRCI and our members

HRCI brings together over 40 national health research charities representing people affected by cancer, rare disease, mental health conditions, dementia, disability and a wide range of chronic illnesses.

For many, research is the only hope. We turn hope into reality by supporting charities to work hand-in-hand with researchers, enabling people and families to influence research decisions, and strengthening national efforts to better understand, prevent and treat health conditions.

HRCI vision and values

Our Vision

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities engaged in health, medical and social care research, collectively representing over 2 million people in Ireland. We champion our members' interests to enhance the environment for health research in Ireland. We empower them to realise our shared vision of improving lives through impactful research.

Note: We define 'health research' to mean research focused on advancing knowledge about human health, wellbeing, illness, care, service provision and population health. We are directly responding to UN Sustainable Development Goal 3: Good health and well-being.

Our values

- We are ambitious and strive to continuously improve and innovate, to accomplish our vision of improving lives through impactful research.
- We are creative, resourceful and unafraid to challenge conventions when we believe there is a better way.
- We are open and transparent, acting with integrity in all our dealings.
- We are always guided in our actions by the needs of our member organisations and the people they serve.
- We value our colleagues and partners, treating each other with fairness, kindness and respect.
- We are collaborative in our approach and prioritise equity, inclusion, and dignity in all our relationships.

Our Strategic aims 2024 – 2027

HRCI has four goals for achieving our vision, as outlined in the HRCI Strategy 2024-2027. We will achieve our vision through leading a vibrant, impactful, and patient-led network of Irish health research charities.

1.

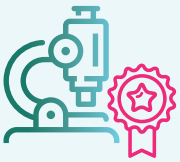
Empower HRCI members in their research activities

2.

Facilitate excellent research through the HRCI-HRB Joint Funding Scheme

3.

Strengthen PPI and the involvement of our members in health research



4.

Positively influence Ireland's health research landscape

How we performed against these objectives is outlined in the Achievements and Performance section.

Our year at a glance

41
Member charities

2million+
People represented

24
National committees and advisory groups

100+
Stakeholders engaged through events

8
Publications, reports and guidance resources

1,600+
LinkedIn followers

87
Shared learning resources

9
Charities in the 2025/26 Joint Funding Scheme round

32
Charities in the Shared Learning Group

HRCI Member Charities 2025

In 2025, HRCI's membership consisted of 41 health research charities. We were delighted to welcome new members, Oesophageal Cancer Fund.

Adelaide Health Foundation
All Ireland Institute of Hospice and Palliative Care (AIIHPC)
Alpha One Foundation
Alzheimer Society of Ireland
Arthritis Ireland
Breakthrough Cancer Research
Central Remedial Clinic
Children's Health Foundation
Cystic Fibrosis Ireland
Cystic Fibrosis Registry of Ireland
Cystinosis Ireland
Debra Ireland
Disability Federation of Ireland
Dublin Neurological Institute
Dystonia Ireland
Emer Casey Foundation
Epilepsy Ireland
Family Carers Ireland
Fighting Blindness
Irish Cancer Society
Irish Heart
Irish Kidney Association (IKA)
Irish Liver Foundation
Irish Lung Fibrosis Association (ILFA)
Irish Thoracic Society
MS Ireland
MSD Action Foundation
Muscular Dystrophy Ireland
Oesophageal Cancer Fund
Parkinson's Ireland
Retina International
Rett Syndrome Association of Ireland
The CRANN Centre
The Rotunda Foundation
The Meath Foundation
Royal Victoria Eye and Ear Research Foundation
Sickle Cell and Thalassaemia Ireland
St John of God Research Foundation
St. Patrick's Mental Health Services
St Vincent's Anaesthesia Foundation
22Q11 Ireland Support Group

Member Story: Irish Cancer Society

Dr Claire Kilty
Head of Research,
Irish Cancer Society

The Irish Cancer Society has had the immense privilege of being a member of Health Research Charities Ireland for many years. As the national cancer charity in Ireland, HRCI provides an invaluable platform to connect with organisations across the health research community, both within cancer and across other disease areas. Through this collaboration, we have been able to come together as a collective voice to advocate for meaningful improvements in health research in Ireland.

I have been personally involved with HRCI since 2018 and have always found the organisation and its network to be an incredibly valuable source of support, insight, and shared learning. It is a welcoming and collaborative community of like-minded individuals, and the opportunities to learn from others have greatly enhanced my own approach to embedding research within the charity sector.

A particular strength of HRCI is its strong commitment to Public and Patient Involvement (PPI). The PPI Shared Learning Group has been an essential resource for my team as we have developed and strengthened our own PPI work within the Society. It provides a trusted space for open and honest discussion, enabling members to share experiences, exchange ideas, and explore best practice in supporting meaningful patient partnerships.

The staff team at HRCI are a genuinely supportive and welcoming group of individuals, always available and willing to assist their members in any way they can. This personalised and member-focused approach makes a real difference, providing reassurance that support is always there when needed.

I was proud to be invited to join the Board of Directors of HRCI in 2024. Being able to contribute to guiding and shaping an organisation from which I have gained so much is a true privilege, and I look forward to supporting its continued growth and impact in advancing health research across Ireland.

Achievements and performance

The following sections offer a thorough summary of our activities throughout 2025; each closely aligned with our strategic aims.

Aim 1: Empower HRCI members in their research activities

At the core of our work is a commitment to empower and support our member organisations in their health research activities. We do this in many ways, but key among them is fostering a sense of community, in which support can come from many places. We also demonstrate leadership, by remaining well-versed and engaged in the health research environment, in order to keep our members informed and prepared. In 2025, we achieved this aim by enhancing capacity through meetings and events, developing and sharing resources and providing personalised and peer support.

Through networking, shared learning and targeted guidance, members developed new partnerships, strengthened research governance structures and expanded opportunities for collaboration with academic institutions.

Facilitating Connection, Collaboration and Research Exchange through HRCI Board and Member Meetings

HRCI Board and Member meetings remained an important forum for our members to connect, share experiences, and discuss common challenges. These gatherings are open to all members, with the exception of one Directors-only meeting held in October. A particular highlight of each meeting is the round table research information exchange, where members share updates on their research activities, leading to valuable conversations and collaborative opportunities. This year, we were also pleased to welcome the following guest speakers to join us at our meetings:

- Simone Walsh, Chair and Programme Manager of the Irish Research Nurses and Midwives Network (IRNM) and a member of the Irish Health Research Forum Steering Group discussed *'The role of the IRNM, advocacy for stable employment and career progression for research nurses and midwives.'*
- Dr Ruth Kelly, Strategy Lead at Research Ireland, spoke about the Research Ireland corporate plan setting out the strategic direction of the new agency for the period 2025-2030.
- Dr Darren Dahly, Principal Statistician, HRB Clinical Research Facility University College Cork presented "*Impact by Design: Understanding the Importance of Getting Research Methodologies Right*."
- Dr Grainne O'Gorman, CEO HRB joined us for a discussion on the role of the HRB and invited feedback from the members on their priorities and asks.

Grainne Gorman, CEO, HRB and HRCI Board and Members attending the December meeting

Mastering Research Impact

In March, we hosted an interactive workshop for our members on how to plan for, track, and communicate the impact of their research-related activities. The session was led by HRCI CEO, Dr Avril Kennan and HRCI Research Support Manager, Dr Sarah Delaney and sought to demystify impact, share useful tools and examples, and give attendees the confidence to navigate all aspects of organisational impact. We were delighted with the turnout on the day and look forward to continuing the discussions around impact at future events.

Attendees at Mastering Research Impact workshop for HRCI members

Shaping Meaningful Research– partnering with Maynooth University

The Maynooth University Research Together event took place in October in St Patrick's College, Maynooth University. The event aimed to foster understanding, build trust, and develop meaningful and lasting partnerships between researchers and charities/civil society organisations.

Three HRCI member charities (Alice Moore, Crann Centre; Ellen Moran, Retina International and Niamh Gavin, Adelaide Health Foundation) presented on their research needs and what good partnerships and meaningful involvement can look like. The event also featured a panel discussion which included HRCI member Alison Cotter of MS Ireland and a design thinking session. Details of national and European funding opportunities from the HRB and the National Contact Point for Horizon Europe were also presented.

This event was a collaboration between Maynooth University Research Development Office, HRCI, and The Wheel. It was a valuable opportunity to connect across the university and charity sectors, build relationships, and identify potential partners to co-develop impactful research projects.

Aim 2. Facilitate excellent research through the HRCI-HRB Joint Funding Scheme

The Joint Funding Scheme, run in partnership with the Health Research Board (HRB), provides HRCI member charities with the opportunity to secure matched funding for research projects that matter to their communities. It promotes international best practice in research governance and is a strong example of meaningful Public and Patient Involvement (PPI). Almost all types of health research can be funded through the Scheme, and it has been particularly beneficial for rare disease research. To date, 163 awards have been made through the Scheme, representing over €28 million in investment.

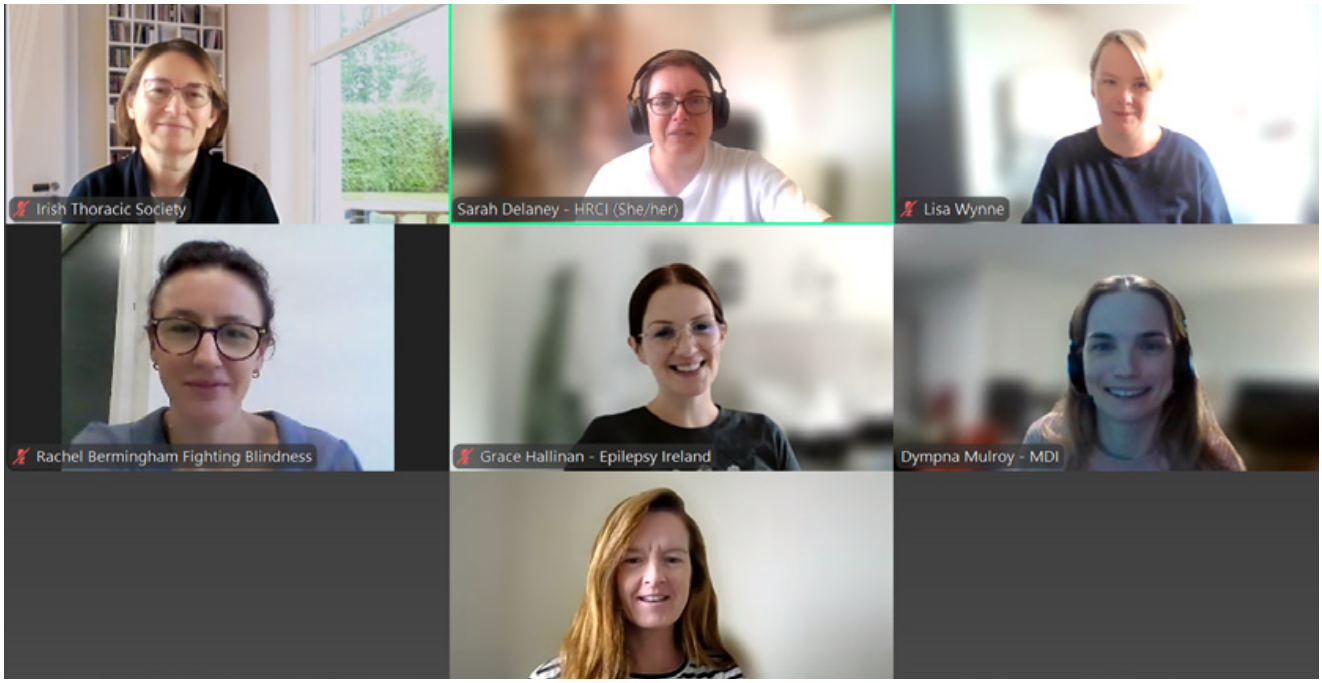
Strengthening the Joint Funding Scheme

Based on feedback from previous rounds and on the recommendations of a recent independent study on the Joint Funding Scheme, we worked with the HRB to make some important changes to the 2025-2026 round of the scheme. A workshop was held in April to seek the views of members on the proposed changes, followed strong engagement with the HRB to agree the changes. These were approved by the HRB Board in June.

The international peer review and applicant response phases are now co-administered by charities and the HRB, facilitated by the use of the HRB's online grant portal. Separately, the relevance of an application is now fully decided by the participating charity, and therefore it is no longer an assessment criterion for review by the expert panel that ranks the applications.

Guidance and Support for Participating Charities

Nine charities participated when the current round of the Joint Funding Scheme kicked off in 2025. We provided comprehensive support along with the HRB via monthly informal Q&A sessions, a dedicated session on the new application process, and an information session on the current round, including an overview of the changes, and how to undertake international peer review. We also maintained an up-to-date set of FAQs on our website and undertook various outreach activities.



HRCI members attending the monthly informal JFS Q&A session in August 2025

These included **a video on the 2025-26 round of the scheme** for researchers which was posted on our website and YouTube channel and shared with university research offices and PPI Ignite offices. The scheme was also presented to researcher networks in the TCD School of Medicine and Epilepsy Ireland. Further engagement included participation in a Maynooth University Social Sciences Institute **seminar** on evidence-based policy, with a focus on the JFS.

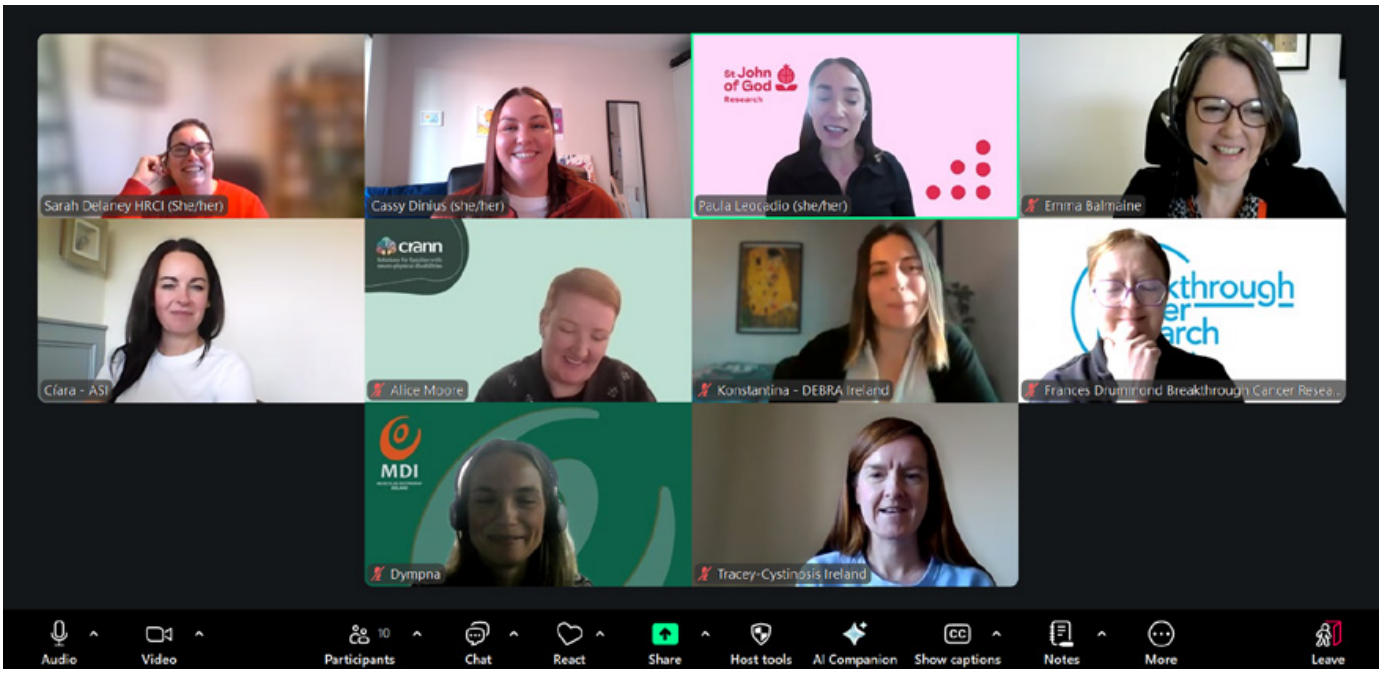
Aim 3. Strengthen PPI and the involvement of our members in health research

We and our members serve as a crucial link between the realms of science and society. With a focus on ensuring meaningful involvement, we support our members as they involve their communities in their research decision-making and as they facilitate researchers to undertake public and patient involvement (PPI). We work to highlight the value and perspectives of our members with the health community and to amplify our efforts through partnerships with other PPI focused groups.

Strengthening Member Capacity through the Shared Learning Group

To build the capacity of our members to advance PPI in health research, and to develop successful partnerships with researchers, we have hosted a PPI Shared Learning Group (SLG) for our members since 2017. This provides a safe space for discussion and knowledge-sharing about PPI.

This year we recognised that many of our members were also looking for an arena where they could share experiences and knowledge about different aspects of research governance that fall within their remit. To meet this need, we consulted with our members and in December 2025 we expanded the scope of the SLG to include both PPI and research governance.



HRCI Members attend the Shared Learning Group meeting in December 2025

In 2025, the HRCI SLG included 54 individuals from 32 different charities. We were delighted to welcome a range of experts to speak to our group, including:

- Lisa Whittaker, Blood Cancer UK, and Anne Croudass, Cancer Research UK, who presented on the emotional impact of PPI.
- Brendan Dolan, University of Galway, who discussed key considerations in assessing the impact of PPI.
- Martha Killilea, University of Galway, who presented on the experience of running a PPI facilitation skills SLG.
- Cassandra Dinius, Rare Disease Clinical Trial Network, who presented a preview of ***A Friendly Guide to Equality, Diversity & Inclusion (EDI) in Public and Patient Involvement (PPI)*** Inclusive Involvement: Practical Steps You Can Take Today

Across the meetings we also addressed topics such as commercial influences on PPI, assessing the impact of PPI, and HRCI's research governance guide. We added 8 new resources to our resource hub for the SLG, bringing it to a total of 87.

Creating inclusive PPI spaces in research

In April, we held a workshop in partnership with the Rare Disease Clinical Trial Network which focused on helping people create inclusive spaces for PPI. The workshop aimed to turn ideas into action, with insights from the day being used to shape a new practical guide subsequently published in 2026. Its practical recommendations will help ensure that diverse perspectives are not only heard but embedded in the research process.

With every attendee rating it as excellent or very good, the event brought together voices from across the rare disease community including PPI partners and HRCI rare disease member charities for panel discussions, themed breakout sessions, and open conversations. This event was funded by PPI Ignite Network @ UCD Seed funding scheme 2024.

From Voices to Action: Building Inclusive PPI Together at the UL Summer school

The UL PPI Summer School offers people a participatory space to network, learn & share innovative PPI in research. HRCI had a strong presence at the 10th Annual Summer School with CEO, Dr Avril Kennan delivering a keynote on 'A Decade of PPI in Ireland – Hope, Hurdles and Honest Reflections' together with guests Maureen Gilbert (PPI partner) and Dr Frances Drummond (Head of Research, Breakthrough Cancer Research).

We were also pleased to co-deliver a "Creating Inclusive PPI: Practical Ideas from the Rare Disease Community" workshop at the PPI Summer School alongside the Rare Disease Clinical Trial Network. The strategies we shared were grounded in insights from the April workshop.

Dr Sarah Delaney and Dr Cassandra Dinius contributing to the UL PPI Summer School through presentations and an interactive workshop

Advancing Public and Patient Involvement in Europe through the European Rare Disease Research Alliance

HRCI is pleased to represent Ireland along with the HRB, UCD and RCSI as a partner in The European Rare Diseases Research Alliance (ERDERA). This partnership brings together over 170 organisations from the public and private sectors to advance prevention, diagnosis and treatment research in rare diseases.

HRCI participates as a partner on the PPIE (Public and Patient Involvement and Engagement) working group, contributing to international collaboration and knowledge exchange on engagement in research. As part of this role, HRCI developed a plan for a PPIE resources hub.

We also presented at the ERDERA General Assembly and at an ERDERA meeting of international research funders and patient organisations, contributing to ongoing international dialogue on PPIE in rare disease research.

Dr Avril Kennan presenting at the ERDERA General Assembly

Partnering for Progress: Our Involvement in the National PPI Ignite Network

Dr Cassandra Dinius and Dr Sarah Delaney attend the PPI Ignite Festival launch October 2025

We are proud to be a member of the PPI Ignite Network, a collaborative platform that serves as a unified voice for PPI in health and social care research across Ireland. Funded by the Health Research Board and the Irish Research Council, this five-year initiative brings together seven universities, 10 national partners, and 64 local partners. As a national partner, we play a significant role and hold the distinction of being the only non-university partner co-leading one of the Network's five work packages.

In partnership with DCU and the University of Galway, we focus on building PPI capacity across communities nationally in work package 1.

As part of this work, HRCI contributes to the development and analysis of the PPI Ignite scoping surveys on PPI training and resources, including a 2025 survey.

We also participated in a broad range of additional PPI meetings, committees and events including the PPI Ignite Network Steering Group.

With Phase 3 of the PPI Ignite Network launching in 2026, we were pleased to confirm our continued involvement as both a National Partner and local partner with UL and DCU. We represented National Partners on the HRB grant review panel for the next phase of the Network and continued involvement in Phase 3 planning through participation in multiple planning meetings.

Aim 4: Positively influence Ireland's health research landscape

Our members collectively represent the interests of over two million people in Ireland, and through their research, they are dedicated to enhancing the well-being of those they serve. As an umbrella organisation, we are uniquely positioned to understand our members' challenges and priorities. We leverage this insight to advocate for advancements in the Irish health research sector, collaborating with policymakers, politicians, and a diverse range of other stakeholders.

To achieve this strategic goal, we run the Irish Health Research Forum, publish annual Position Papers, sit on 24 national committees and engage in numerous advocacy initiatives.

HRCI Position Paper 2025: Enhancing health research in Ireland

In the Health Research Charities Ireland Position Paper 2025, we outlined the top priorities for both HRCI and our members, aimed at enhancing health research in Ireland. While there were many aspects of health research in need of attention and support, we believed it was both urgent and opportune to address these recommendations. In consultation with our members, Health Research Charities Ireland developed three key asks for elected representatives and policymakers in 2025.

Advocating for health research

We were pleased to have the opportunity to discuss the key asks outlined in the HRCI Position Paper 2025 with Minister for Health, Jennifer Carroll MacNeill T.D. in May. A central focus of the discussion was our members' priority for the Health Service Executive Action Plan for Health Research 2019–2029 to be adequately resourced. At the request of the Minister, we subsequently prepared a report with three case studies on how research is being embedded within the health system.

Dr Avril Kennan; CEO, HRCI, Jennifer Carroll MacNeill T.D and Brian Lynch; Chair, HRCI

Dr Avril Kennan; CEO HRCI, Peter Roche T.D. & Linda McGrath; Events & Communications Manager, HRCI

We also had the opportunity to meet with Padraig Rice T.D. (Chair of the Oireachtas Committee on Health), Peter Roche T.D., and Senator Manus Boyle to discuss the Position Paper. Constructive engagement of this kind is vital to ensuring that the voices of our members and the wider health research community are heard and reflected in national policy. We subsequently submitted PQ's on biobanking legislation and the National Research Ethics Bill.

Following the publication of the draft **Programme for Government**, HRCI CEO Dr Avril Kennan wrote an opinion piece, which examined what it meant for health research. Many of the commitments in the Programme for Government 2025 are broad, leaving scope for ministers and officials to engage with the health research community towards practical and innovative approaches.

Towards the end of 2025, the Department of Enterprise, Tourism and Employment launched a public consultation to help shape a new National Life Sciences Strategy - a key commitment in the Programme for Government 2025: Securing Ireland's Future.

HRCI made a submission to this consultation helping to ensure that the collective voice of our members is reflected in its development. We called for it to be aligned with public priorities and with improved health outcomes clearly at its core. We emphasised the importance of working not just for patients but with them and highlighted the valuable role that charities can play as partners in the strategy's development and implementation.

Managing the Irish Health Research Forum - A single voice for health research

The Irish Health Research Forum, which is run by HRCI, brings together all stakeholders nationally to positively influence health research. The Forum holds events that examine important health research topics and puts forward recommendations. These events have gained national recognition for their exceptional quality and ability to attract diverse attendees. Reports for all meetings of the Irish Health Research Forum, including agendas and recommendations, are available on our website.

The outputs from these events are widely used and cited by policymakers and stakeholders in the ongoing discussions around health research in Ireland. As an independent organisation, representing 40+ charities and with a strong patient-focus, HRCI is ideally placed to bring people together to tackle the big issues in health research and to bring about change. We are supported in all Irish Health Research Forum activities by an exceptional and diverse Steering Group of leaders. For more information, see: https://hrci.ie/irish-health-research-forum-steering-group/

A year of the Irish Health Research Forum

In April, we launched the report from the November 2024 Irish Health Research Forum, Public trust in health research: are we doing enough? At the Forum, we delved into the critical role different actors can play in fostering trust in health research. We explored how these groups can be proactive and work together to ensure that health research is not only rigorous but also resonates with the values and expectations of the public. By bringing diverse perspectives to the table, we sought to identify practical approaches for enhancing trust, ultimately leading to more understanding and acceptance of research and its outcomes. Attendees contributed their perspectives through discussion groups and a robust Q&A session.

Nuanced by input from our expert Steering Group, the event report offers two overarching recommendations alongside a series of recommendations directed towards researchers, research funders, charities and PPI contributors, research institutions, the Department of Health and the media at large. These practical and achievable recommendations aim to build and maintain public trust in health research into the future.

The Irish Health Research Forum in May, ***Is it time to get serious about patient registries?*** explored the evolving role of patient registries in an increasingly connected and data-driven health landscape.

From small, internationally-linked rare disease registries to large-scale national registries for chronic conditions, the event considered how registries can add value and be supported to maximise their impact – supporting better care, advancing research, and informing policy.

The practical and achievable recommendations in the ***event report*** aim to facilitate a forward-looking, inclusive and shared vision for the next generation of patient registries. A snapshot of the event can be found here on our website.

The Irish Health Research Forum hosted two discussion-based workshops in Dublin (November) and Cork (December) focused on strengthening how the health research community communicates the value of research to policymakers, politicians, and the public.

The interactive sessions explored the language, stories, and messaging approaches that help connect health research to real-world impact and encourage greater investment and attention for the sector. We welcomed Ben Bleasdale of the UK Campaign for Science and Engineering to the Dublin event and our guest for Cork was Prof Nicola Mountford, Maynooth University. Participants gained practical communication strategies and increased confidence in explaining the importance of health research to a range of audiences. Insights from the workshops also contributed to the development of a guide to support clear and consistent messaging across the sector which will be published in 2026.

Feedback from attendees at the Irish Health Research Forum 2025

As always, a great event. Excellent speakers and use of the discussion groups was very beneficial. Thank you.

Caroline Lamb; HSE Research and Development Officer, HSE

Thank you for organising this event and for the work you do. I am with a patient association, and we benefit enormously from the resources and information you provide.

Barry McGrath; HS Ireland & PPI contributor

Informative and inspiring event. Great to see the diverse range of participants with expertise and experience in registries activity. Collaborative learning is key.

Alana Ward; Senior Information Scientist, National Rare Diseases Office

Irish Health Research Forum recommendations influence policy and direction of travel for our health and social care research systems.

Professor Sean Dineen; Clinical Lead, NDR, University of Galway

It is essential to have these stakeholder forums; a democratisation of health service and research development.

Ricardo Segurado Associate Professor of Public Health Biostatistics, University College Dublin.

Proudly representing our members on a national platform

Throughout 2025, we continued to engage with key stakeholders and partners to advocate for progress and investment in health research. We are grateful to the many organisations that connected with us, collaborated with us, and included us in their important work and initiatives. Highlights from our engagement activities during the year included:

- Contributing to a consultation on the HRB's new strategy.
- Supporting Research Ireland in developing a Health and Well-Being Challenge Call and being invited to speak on the perspective of societal partners at their associated brokering event.
- Joining the All-Ireland Research Culture Network.

- Co-chairing a HSE Communications & PPI Working Group supporting implementation of the National Strategy for Genetics and Genomics.
- Participating in numerous national committees including:
    - National Mental Health Research Strategy Implementation Steering Group
    - The Scientific Advisory Board for the Wellcome-HRB St James's Clinical Research Centre.
    - ARC (Accelerating Research Commercialisation) Hub Governance Committee
    - The Genome Data Infrastructure Governance Group
    - The Project Advisory Group for the Trinity College Dublin-led ENGAGED project focused on co-creating Ireland's public engagement and open research roadmap.

Advancing Rare Disease Research Through Partnership

Approximately one-third of HRCI member organisations represent patients living with rare diseases or support research into these conditions. While more than 6,000 rare diseases have been identified worldwide, collectively rare diseases affect a significant number of people across Ireland, many of whom face common challenges including limited research, delayed diagnosis, insufficient expertise, inadequate treatment options, and social isolation. In response, HRCI remains strongly committed to advancing rare disease research and ensuring that the patient voice is central to this work.

RARE DISEASE CLINICAL TRIAL NETWORK

UCD DUBLIN University College Dublin Ireland's Global University

HRCI Health Research Charities Ireland

A key part of this commitment is our partnership with the Rare Disease Clinical Trials Network (RDCTN), an HRB-funded national network working to increase rare disease clinical trial activity in Ireland through collaboration between patients, researchers, clinicians and industry. Together with UCD, HRCI is proud to support the Network through the hosting of a dedicated PPI Liaison Officer role, which strengthens Public and Patient Involvement across rare disease research and clinical trials. The Liaison Officer facilitates a panel of patient and public contributors, supports research prioritisation activities, and delivers workshops and engagement opportunities that empower patients, families and researchers to work collaboratively in shaping the future of rare disease research in Ireland.

RDCTN and HRCI staff attend the launch of the National Rare Disease Strategy 2025-2030

We were delighted to attend the launch of the National Rare Disease Strategy 2025-2030 in the Department of Health in August. We warmly welcomed the Strategy's strong commitments to foster innovation in rare disease research and to establish a National Rare Disease Registry.

Prof Rachel Crowley, Dr Cassandra Dinius and Dr Avril Kennan attended a meeting of the All-Party Oireachtas Group on Rare Diseases in July

Communicating the value of health research

Throughout 2025, we remained dedicated to maintaining robust communication channels to support and enhance our activities. We worked hard to keep our members informed of relevant research news, opportunities, funding updates, events and publications.

- We added an Impact page to the HRCI website which outlines the impact our work has had across the Irish Health Research Forum, PPI, member support and the Joint Funding Scheme.
- Continued to grow our followers on LinkedIn, ending the year with over 1600 followers (from 1000 in 2024).
- Grew our presence on Bluesky and encouraged any members who joined the platform to connect with us.
- Uploaded all our publications to Lenus, the Irish health repository.
- Issued 3 newsletters during the year highlighting JFS calls, the Irish Health Research Forum workshops and events and spotlighting member news to over 2000 mailing list recipients.
- Featured in the HRB's annual Health Research in Action publication, highlighting success stories in health and social care research.
- Shared an opinion piece written by HRCI CEO Dr Avril Kennan which examined the Programme for Government and what it means for health research.
- Uploaded new content to our YouTube channel including an introduction and overview for researchers of the HRCI/HRB Joint Funding Scheme and a video created for the 2025 Irish Health Research Forum event, "Is it time to get serious about patient registries?" Patient Registries: From Data to Better Care**.** The video brings together the voices of patients, advocates and clinicians to explore how registries can transform care, drive research, and support better decision-making. We also highlighted INVISIBLE - A spoken word film on why diversity in PPI & health research matters for everyone and a presentation Dr Darren Dahly gave at our Board and members meeting in September on Ensuring Impact Through Rigorous Research.

HRCI governance

Health Research Charities Ireland believes that good governance means being clear in our objectives, ethical and transparent in our dealings, accountable to our stakeholders, and compliant with legal requirements. It is a way of working rather than a mere checklist. It represents a commitment, from the Directors down, to operate in the best possible way at all times for the benefit of all our member organisations, their communities and all stakeholders. As an umbrella organisation for other charities, it is particularly important that Health Research Charities Ireland acts as a positive example in all aspects of governance. We have earned the trust of our members and funders, and we must work diligently to retain that trust.

Overview of HRCI Governance:

- Our Board first signed off on our compliance with the Charities Governance code in 2019 and now approves it on an annual basis. We meet all its core standards and are compliant to a level that would be expected of a charity many times our size.
- Our Board of Directors meets six times per year and, in the spirit of transparency and inclusion, five of these meetings are open to all member charities.
- Our Staff and Finance Board Sub-Committee meet five times per year.
- Our Advocacy and Communications Board Sub-Committee meet three times per year.
- Our Appointments Board Sub-Committee meets as required, to advise on appointments of Directors, Chairs, and committee members.
- All governance documents are stored on a secure, online cloud storage service (Tresorit) and are available for review at any time by the HRCI Directors.
- We undergo an annual independent financial audit. Our statutory financial statements are SORP compliant (in line with the Statement of Recommended Practice, Accounting and Reporting by Charities) and made publicly available on our website.
- In addition to our statutory Directors' Report, we produce in-depth and engaging annual reports, reviewing our progress against our strategic goals.
- We maintain a risk register which is reviewed annually.

- We have a strong HRCI Strategy 2024-2027, which sets clear priorities for the organisation and an organisational structure capable of implementing it.
- We update the Governance Compliance Record Form, as advised by the
- Charities Governance Code, which is reviewed and approved by the Board annually.
- We are compliant with all relevant legislation including the Charities Act 2009, the Companies Act 2014, the Lobbying Act 2015, GDPR, employment legislation and equality legislation.
- We have many policies and controls in place to guide our operations. They can be broadly divided into financial and risk policies, HR policies, terms of reference, codes of practice and membership policies. We continually review and update our policies and procedures according to a documented review schedule, with all updated policies approved by the Board.
- We provide detailed reports to our funders (Pobal and the HRB) and are very focused on how best to measure and report our impact, beyond simple outputs.

HRCI Structure

We have eleven highly experienced people on our Board, all bringing important perspectives. While they are there as independent individuals representing the best interests of HRCI, many are drawn from the HRCI membership. Other places are open to people from external organisations who bring additional perspectives. There is no remuneration of Directors, and all work is done on a voluntary basis.

HRCI Board Members

Chair: Brian Lynch

Brian Lynch is Operations Manager and Deputy Head of School – Partnerships, RCSI School of Population Health. He represents HRCI on the Irish Health Research Forum Steering Group and represents the RCSI School of Population Health at the Health Promotion Alliance Ireland (HPAI). He holds master's degrees in public health and digital marketing and is a member of the Association for Health Promotion Ireland (AHPI). He is a director of the Rutland Centre. Prior to joining RCSI, Brian was Head of Communications and Advocacy, Arthritis Ireland.

Secretary: Dr Sinéad Hickey

During this period**, Dr Sinéad Hickey** was the Head of Advocacy, Research and Policy at Debra. She is now Senior Research Programme Manager of Precision Oncology Ireland at Systems Biology Ireland, UCD. She has 20 years' experience in biomedical and skin research, leading national and international collaborative projects and advancing Public and Patient Involvement (PPI) in research. She previously led advocacy, research and policy at Debra, supporting people living with epidermolysis bullosa (EB), and served on the executive committee of the national EB registry and as an ePAG member for ERN Skin.

Treasurer: Jonathan O'Connell

Jonathan O'Connell is Chief Financial Officer with Phoenix Technologies. He has over 25 years' experience in managing companies during periods of high growth in the technology and life science industries combined with extensive expertise in leading and managing fundraisings, public listings, acquisitions and trade sales.

During this period **Dr Laura Brady** was Digital Health Innovation Lead at the FutureNeuro SFI Research Centre, driving a data and digital health strategy towards enriched health and wellbeing for people living with neurological disease. Previously, she managed a Disruptive Technology Innovation Fund initiative at RCSI University of Medicine and Health Sciences. Prior to that, Laura was Head of Research at Fighting Blindness where she led their research strategic plan 2017-2021, heightened capacity around public and patient involvement and coordinated Target 5000, a national registry for rare retinal disease. Laura holds a B.A. (Mod.) and a Ph.D. in Biochemistry from Trinity College Dublin, along with a Professional Diploma in Leading Digital Health Transformation from RCSI.

Dr Lesley O'Hara is the Chief Executive Officer of the Saint John of God Research Foundation clg. Saint John of God provides mental health and intellectual disability services throughout Ireland, the UK, and Malawi. Lesley is responsible for the strategic development of research activities across these services, ensuring that a culture of research and innovation is promoted and supported through a robust governance structure, annual research funding scheme, and the delivery of research education and training. Dr O'Hara has a PhD in critical health psychology, with a focus on the lived experience of managing chronic illness. Her subsequent post-doctoral research has explored mental health including eating disorders, and the transition from child to adult mental health services across Europe.

Dr Frances Drummond has been working as Research Manager with Breakthrough Cancer Research since October 2019. Having qualified with a PhD in Biochemistry from University College Cork, Frances shifted her focus to patient focused research for her post-doctoral career. She has fifteen years of experience in cancer research in the National Cancer Registry of Ireland and University College Cork. Frances has published more than 60 peer-reviewed papers and reports. She is also a fully IACP accredited counsellor and psychotherapist. Frances believes passionately that research is vital to improve health and survival at both the individual and the population level.

Dr Claire Kilty is the Head of Research at the Irish Cancer Society. As part of her role, she leads the research team to oversee the Irish Cancer Society research funding portfolio, implements cancer research strategy, and communicates to the public about the research funded by the Society as well as the latest cancer research developments.

Claire is extremely passionate about ensuring that the patient voice is at the heart of cancer research and manages the Society's public and patient involvement panel. She works together with people affected by cancer to ensure public and patient involvement in research is central to both the Irish Cancer Society's research funding processes and the national cancer research community.

Prior to her role in the Society, Claire was Research Manager in UCD working on developing a One Health Research strategy across the university. She has also previously worked as Programme Manager for the UCD Conway Institute of Biomolecular and Biomedical Research; BREAST-PREDICT, Irish Cancer Society's first Collaborative Cancer Research Centre; and SYS-MEL, an EU FP7 funded Industry- Academia Partnerships and Pathways grant. Claire has a PhD in Genetics, and three years postdoctoral experience working in ocular drug discovery.

Dr Bernadette Rock is Head of Research and Regulatory Data Insights at the Medical Council, where she contributes to developing and implementing its research programme and supporting functions across the Council. Previously, Bernadette worked in The Alzheimer Society of Ireland as Policy and Research Manager, where she developed and implemented a national dementia research strategy. Bernadette is keenly interested in supporting and empowering the patient/public voice in research. This is reflected in her research roles in The Alzheimer Society of Ireland, National Children's Hospital and the Childhood Development Initiative. Bernadette is a graduate of Trinity College Dublin and University College Dublin, where she obtained a Masters in Sociology and Social Research and a PhD in Sociology.

Niamh Gavin has served as CEO of the Adelaide Health Foundation [AHF] since 2016. The AHF are an independent charity focused on advancing and promoting equitable access to healthcare services and education in Ireland, through support of education and research.

Niamh is passionate about the organisation's mission to advance healthcare and as CEO, works with AHF Board and team to deliver the organisation's strategy through community, research and education programmes. In her current role, Niamh works with stakeholders in Tallaght University Hospital, TCD, the HSE, government departments and local community organisations.

Prior to joining the AHF, Niamh worked on the Executive of The Wheel, Ireland's national association of charities, community groups and social enterprises, which is where her interest in charity governance was honed. Before moving to work full time in the community and voluntary sector in 2012, Niamh held several management positions in the private sector.

Dr Sarah Tecklenborg was appointed CEO of Cystic Fibrosis Ireland in 2024. Sarah joined CFI in December 2019 as Senior Research and Policy Coordinator, bringing extensive research and management experience with her. Since then, Sarah established Public and Patient Involvement (PPI) programmes, support groups such as the Pregnancy Support and Advocacy Group, and has been instrumental in campaigning for better CF care and access to medications.

Prior to CFI, Sarah worked in the HSE Sexual Health and Crisis Pregnancy Programme and the Health Research Board. Dr Tecklenborg graduated from Trinity College Dublin with a BA in Microbiology, a MSc in Global Health and a PhD in Molecular Epidemiology. Following this she undertook three post-doctoral research positions in the Royal College of Surgeons in the areas of Epidemiology, Sexual Health and Pharmacoeconomics.

Mike Walsh is Head of Specialist Services, Research & Education with the Central Remedial Clinic.

HRCI Board responsibilities

The HRCI Board is responsible for:

- The establishment and continued adherence to a governance framework and compliance with the Charities Governance Code.
- Setting strategic direction for the organisation in accordance with the HRCI constitution.
- Overseeing financial performance of the organisation in accordance with defined HRCI financial processes.
- Overseeing executive performance of the organisation.
- Overseeing subcommittee membership and performance.

The HRCI Board ensures the organisation is both effective and accountable and ultimately takes responsibility for all activities of the organisation. On appointment to the HRCI Board, all Board members are invited to avail of Board and governance training, provided by The Wheel. HRCI has also developed a comprehensive Guide for Board Members which outlines the responsibilities of Board members and provides practical information on supports and resources available to assist them in carrying out their duties.

HRCI Board Competency

We maintain a broad competency matrix and continually assess the competencies of our Board to ensure that all necessary skills and experiences required to provide leadership and good governance are in place. The most recent review of Board competency was conducted in 2024.

Competency was measured across the following areas: Finance, HR, Advocacy/ campaigning, PR, Communications, Governance, Risk Management, Strategy, Legal, and Income generation. The Board was deemed to have some competency in all areas, with very strong competency in most. The areas in which we are least strong are in legal expertise and income generation. We mitigate this by seeking external expert opinion when required.

Board Terms & Conflict of Interest

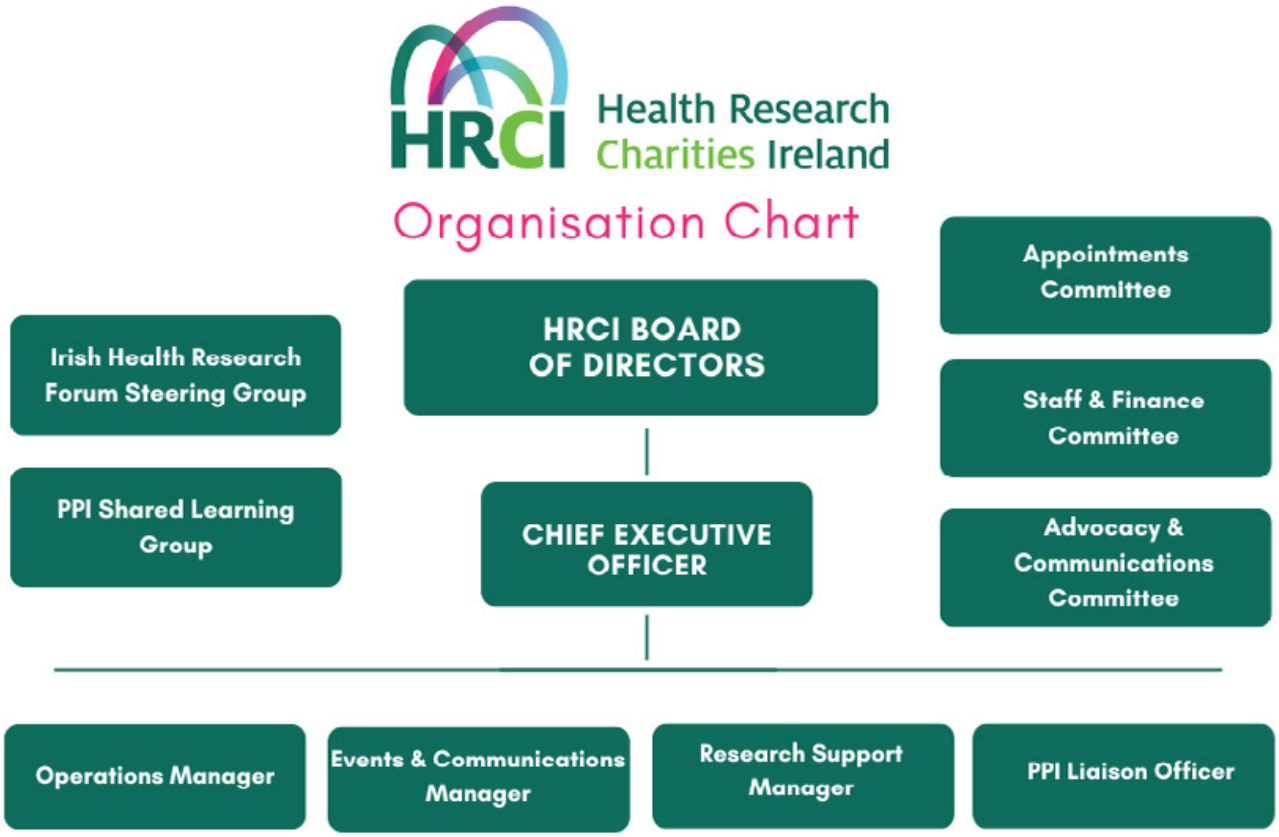
In line with the HRCI Constitution and adhering to the best practices outlined in the Charity's Governance Code, the maximum term for directors is capped at 9 years. HRCI ensures that each director signs a Code of Conduct Policy and adheres to a Conflict of Interest Policy, both of which are reviewed every three years.

Furthermore, HRCI provides an induction pack to new Board members, which includes a Board Member Handbook, the HRCI Constitution, HRCI Strategic Plan, the Annual Staff Workplan, and a link to the storage of HRCI Policies and Procedures.

Attendance at Board meetings:

The HRCI Board of directors met five times in 2025. Attendance at these meetings by Board members is indicated by a tick in the following table:

Name	13 Feb	2 Apr	10 Jun	11 Sep	3 Dec
Jonathan O'Connell		√		√	√
Laura Brady*	√				
Sinéad Hickey	√		√	√	√
Frances Drummond	√	√	√	√	√
Michael Walsh*	√	√	√		
Bernadette Rock	√	√	√	√	√
Brian Lynch	√	√	√	√	√
Lesley O'Hara	√		√	√	√
Niamh Gavin	√	√	√	√	√
Claire Kilty	√	√		√	
Sarah Tecklenborg	√	√	√	√	√



HRCI Subcommittees

Health Research Charities Ireland has three subcommittees which help guide and oversee the organisation.

i) Staff and Finance Subcommittee

This committee meets five times per year and its purpose is to:

- Advise the HRCI CEO on all aspects of staff and finance.
- Review HRCI governance policies and practices.
- Consider and approve new HRCI member applications.
- Advise the HRCI CEO on wider issues of sensitivity that cannot be addressed at Board and member meetings.
- Address issues of non-compliance with the member and Director codes of conduct, which cannot be resolved by the Chair.
- Where necessary, to make recommendations to the Board of HRCI on issues the Committee has considered.

In 2025, the Staff and Finance Committee was composed of the following members:

Sinead Hickey (Committee Chair)
Jonathan O'Connell (Treasurer)
Brian Lynch (HRCI Chair)
Bernadette Rock (Director)
Niamh Gavin (Director)
Laura Brady (Director – stepped down June 2025)
Mike Walsh (Director - stepped down June 2025)
Avril Kennan (HRCI CEO)

ii) Advocacy and Communications Subcommittee

This committee meets three times per year and its purpose is to:

- Advise and make recommendations to the HRCI Board and staff on all aspects of advocacy and communications.
- Help ensure the advocacy and communications activities of HRCI are responding to the needs of the HRCI membership and reflective of their views.
- Provide guidance on HRCI advocacy and communications strategies.
- Act as ambassadors for HRCI, in order to increase our profile and to reach out to possible new members and relevant stakeholders.

In 2025, the Committee was composed of the following members:

Lesley O'Hara (Director & Committee Chair – appointed April 2024)
Suzanne Dowd (HRCI Member)
Ciara Cotter (External expert)
Fiona Aherne (HRCI Member)
Neil Ward (HRCI Member)
Bernadette Rock (HRCI Director)
Frances Drummond (HRCI Director)
Sinead Hickey (HRCI Director – stepped down June 2025)
Mary Nicholson (HRCI Member – joined June 2025)
Carl Gibney (External expert - joined February 2025)
Mark Murphy (HRCI Member - joined February 2025)
Avril Kennan – (HRCI CEO)

Staff attending by invitation: Linda McGrath

(iii) HRCI Appointments Committee

This committee meets at least once a year before the AGM, and as otherwise required. It is entrusted with the responsibility of recommending the appointment of new Directors to the Board. Additionally, the Committee plays a pivotal role in guiding the selection of the HRCI Chair, members for the Board sub-committees and the Chair of the Irish Health Research Forum Steering Group. The Committee operates in alignment with HRCI's overarching mission and governance policies.

In 2025, the Committee was composed of the following members:

Bernadette Rock (Committee Chair)

Brian Lynch (HRCI Chair)

Sinead Hickey (Director)

Claire Kilty (Director - joined June 2025

Laura Brady (Director – stepped down June 2025)

Avril Kennan (HRCI CEO)

Staff attending by invitation: Marie Downes

HRCI Staff Members

Dr Avril Kennan is CEO of Health Research Charities Ireland (HRCI), a national organisation that brings together over 40 health research charities representing people affected by cancer, rare disease, mental health conditions, dementia, disability and a wide range of chronic illnesses.

HRCI works to turn hope into reality by supporting charities to engage in research that improves lives. Under Avril's leadership, the organisation strengthens partnerships between charities and researchers, enables people and families to influence research decisions, and advances national efforts to better understand, prevent and treat health conditions.

She leads the Irish Health Research Forum, bringing together stakeholders to shape better health research in Ireland, and oversees the Joint Funding Scheme with the Health Research Board, which has funded over 160 projects aligned with member priorities.

Avril holds a PhD in genetics, previously worked as a molecular biologist, and held senior roles in DEBRA Ireland and DEBRA International.

Marie Downes, HRCI Operations Manager, is primarily responsible for HRCI general operations including securing core funding, managing accounts, membership management and governance. Marie has a background in IT Project Management and has held management positions and led teams within Bank of Ireland Finance, EDS (now merged with HP) and AranTech (now acquired by Tektronix). Marie began working with HRCI in 2010 as the sole employee of the organisation.

Linda McGrath is HRCI's Events and Communications Manager, overseeing events including workshops, webinars, the Irish Health Research Forum, and HRCI/ HRB Joint Funding Scheme celebrations. She leads communications with key stakeholders and coordinates the Irish Health Research Forum Steering Group and HRCI Advocacy and Communications Committee.

Since joining the charity sector in 2012, Linda has worked across events, fundraising, sponsorship, public affairs, and communications. She serves on the Board of Dublin Lesbian Line and previously worked with Temple Street Foundation, Dublin Simon Community, and in arts management.

Sarah Delaney is HRCI's Research Support Manager. Sarah is responsible for strengthening the research capacity of HRCI members, managing the HRCI/HRB Joint Funding Scheme, supporting patient and public (PPI) involvement in research and engaging with relevant bodies and organisations on all aspects of health research in Ireland.

Sarah has many years' research experience working in the field of health and social care for older people, family carers, and people with chronic illness. She worked with the Royal College of Surgeons conducting research on public and patient participation in health care, and care and case management for older people. Later, as Senior Research Consultant with the Work Research Centre, she gained valuable experience in research at National and European levels, focusing on evaluating health service users' experiences of health technologies. She was awarded a PhD on self- management in chronic obstructive pulmonary disease (COPD) in September 2020.

Dr Cassandra Dinius is jointly appointed between Rare Disease Clinical Trials Network and HRCI as a Public and Patient Involvement (PPI) Liaison Officer. She is responsible for expanding the involvement of patients, their families, and members of the public in the design and conduct of trials in rare disease. In her role, Cassandra is developing a Rare Disease Patient Advocacy Group, delivering conferences for patients and investigators, and engaging with patient collaborators on development of new Patient Reported and Patient Centred Outcome Measures.

Cassandra has over a decade of research experience in enhancing brain health and well-being with older adults using community-based and lifestyle interventions. She enjoys collaborating with interdisciplinary and interinstitutional teams to build practice around engaged research.

Remuneration and Performance Management

All staff salaries are reviewed annually by the Staff & Finance Committee, which considers benchmarking data, inflation, charity funds, and employee performance to determine appropriate remuneration for each employee. Salary benchmarking publications, including Pay and Benefits in the Community and Voluntary Sector from The Wheel, are used as key inputs in these reviews.

High-level goals are outlined in the HRCI Strategic Plan, and each staff member has an agreed-upon annual work plan with tasks aligned to these overall goals. Annual performance reviews are conducted for all staff, during which activities from the past year are assessed, and tasks for the upcoming year are established.

Acknowledgements for Funding

We would like to thank our funders without whose support we would not have been able to function in 2025:

Rialtas na hÉireann
Government of Ireland

pobal
government supporting communities

HRB Health Research Board

The Scheme to Support National Organisations is funded by the Government of Ireland through the Department of Rural and Community Development.

Pobal SSNO funding

We are grateful for Pobal SSNO funding, 2023-2027 to support many of our core activities.

Health Research Board

We are grateful for HRB funding to support our activities relating to the Joint Funding Scheme.

Investments

HRCI does not hold any investments.

Legal Representatives

HRCI does not retain legal services. On an as-needed basis, we have previously used the services of Mason Hayes Curran who are experienced providers of legal services to the Charity and Not-for-Profit sector in Ireland.

Company Details

Charity Number: CHY 15386

Company Number: 377794

Company Address: HRCI, Digital Office Centre, 12 Camden Row, Dublin 8, D08R9CN

Contact Details: Avril@hrci.ie

Audited Accounts

Abridged Annual Accounts 2025.

Full accounts for 2025 are available on the HRCI website - www.hrci.ie

Financial statements

Directors' Report

Directors Responsibilities statement

Independent Auditor's report to the members

Statement of Financial Activities

Balance Sheet

Directors' Report

The directors present their annual report and audited financial statements for the year ended 31 December 2025.

Reference and Administrative Details

The organisation is a charitable company with a registered office at Digital Office Centre, 12 Camden Row, Dublin 8. The company's registration number is 377794.

The charity has been granted charitable tax status under Sections 207 and 208 of the Taxes Consolidation Act 1997, Charity No CHY 15386 and is registered with the Charities Regulatory Authority, Registered Charity Number 20052973.

Directors and Secretary

The names of persons who at any time during the financial year and since the year end unless otherwise stated were directors/trustees of the company are as follows:

Jonathan O'Connell (Treasurer)

Laura Brady (Resigned 10 June 2025)

Sinéad Hickey

Claire Kilty

Frances Drummond

Michael Walsh (Resigned 10 June 2025)

Niamh Gavin

Bernadette Rock

Brian Lynch

Lesley O'Hara

Sarah Tecklenborg

Secretary

Sinéad Hickey

Principal Activities and Objectives

Health Research Charities Ireland (HRCI) is the national umbrella organisation of over 45 charities engaged in health, medical and social care research, collectively representing over 2 million people in Ireland.

We champion our members' interests, to enhance the environment for health research in Ireland. We empower them to realise our shared vision of improving lives through impactful research.

We offer our members the potential for matched research funding through the Joint Funding Scheme, run in partnership with the Health Research Board. We also run the Irish Health Research Forum, bringing together all stakeholders to improve health research in Ireland. www.hrci.ie

Financial review, achievements and performance

We are pleased to present the 2025 HRCI Directors' Report, reflecting a year of sustained activity, strong collaboration and continued leadership across Ireland's health research landscape. Guided by our Strategy 2024–2027, the Board and staff team worked closely with members and partners to advance high-quality, inclusive and impactful health research.

2025 was marked by particularly strong member engagement across our activities, alongside the deepening of national and international partnerships that enabled us to extend our reach despite limited resources. We also strengthened our advocacy efforts through engagement with politicians and policymakers, as well as active participation in committees and advisory groups. As always, the dedication of our members, partners and staff team has been central to our progress.

Below we outline key achievements across each strategic goal, alongside the underpinning activities that support our work. Further detail is available in the 2025 HRCI Annual Report.

Goal 1: Empower HRCI members in their research activities

Supporting members to confidently engage in and shape health research remains a core focus of HRCI's work. Throughout 2025, we strengthened member capability through shared learning, workshops, collaborative events and tailored one-to-one support.

We held four meetings of the HRCI Shared Learning Group and expanded its remit to include research governance and management alongside Public and Patient Involvement (PPI). Board and Member Meetings continued to provide valuable networking and engagement opportunities, with guest speakers including Prof Gianpiero Cavalleri (Genome of Ireland), Simone Walsh (Irish Research Nurses and Midwives), Dr Ruth Kelly (Research Ireland), Dr Darren Dahly (biostatistician) and Dr Gráinne Gorman (HRB), reflecting the breadth of issues relevant to our members.

A key initiative was a dedicated workshop on charity research impact, focusing on how to plan for, capture and communicate impact in a research context. We also partnered with Maynooth University Research Development Office to deliver the fourth "Research Together" event, showcasing collaborative projects between researchers and HRCI member organisations.

In addition to group activities, we provided ongoing tailored support to members across a wide range of areas including funding, research strategy development, patient registries, public and patient involvement (PPI), ethics, communications and recruitment.

Goal 2: Facilitate excellent research through the HRCI-HRB Joint Funding Scheme

The HRCI-HRB Joint Funding Scheme (JFS) remained a central pillar of our work. Through this Scheme, HRCI member charities can co-fund research addressing the needs of their communities with the HRB.

During 2025, our focus was on refining the scheme, supporting participating charities and strengthening collaboration with the Health Research Board (HRB).

Building on feedback from the 2023–2024 round and the findings of an independent Maynooth University study, the HRB worked with us to introduce significant refinements to make the scheme even more supportive for charities, including increased HRB involvement at earlier stages. These proposed changes were shaped through a dedicated member consultation process.

We supported nine charities through the early stages of the current round through information sessions, guidance materials, videos, FAQs and direct engagement. Communications relating to charity funding calls were amplified across academic networks via university research offices and PPI Ignite teams. We also presented on the Joint Funding Scheme at external academic and policy events, raising awareness of this unique Scheme.

To highlight impact, we produced a case study on the 2024 HRCI Research Impact Award winner, demonstrating the long-term value of collaborative funding.

Goal 3: Strengthen PPI and the involvement of our members in health research

HRCI continued to play a leadership role nationally and internationally in advancing meaningful, inclusive public and patient involvement (PPI) and supporting the involvement of health charities in research.

We convened four meetings of our PPI Shared Learning Group, addressing topics such as recruitment, emotional impact, payment, evaluation and impact assessment. Our valued partnership with the Rare Disease Clinical Trial Network continued, through which we co-host a PPI role delivering mutual benefits for both organisations.

Through this partnership we delivered two workshops on inclusion in PPI in Dublin and Limerick.

Through the PPI Ignite Network, we contributed to work package activities, governance committees and preparations for the next phase of funding, while representing National Partners at a HRB review panel meeting. Internationally, we played a leadership role in the European Rare Disease Research Alliance (ERDERA), contributing to a PPI working group, helping to shape a resource hub and delivering key PPI messages through presentations to international audiences.

We also maintained extensive engagement related to this goal across a range of national and international committees and advisory groups, including co-chairing the HSE National Genetics and Genomics Working Group on PPI and Communications.

Goal 4: Positively influence Ireland's health research landscape

Advocacy and policy engagement remained a significant area of focus in 2025. Through publications, events and direct engagement with policymakers, we worked to amplify the collective voice of health research charities.

We published the 2025 HRCI Position Paper, setting out three key recommendations for politicians, and met with members of the Oireachtas Health Committee to discuss its priorities. We also met with the Minister for Health and senior officials from the Department of Health and HSE, and at the request of the Minister for Health, prepared a report highlighting case studies on embedding research within HSE regions. Additional policy engagement included publishing an analysis of the Programme for Government, making a submission to the consultation on the National Life Sciences Strategy, and engaging with Research Ireland and the HRB through consultations on their strategic plans.

The Irish Health Research Forum continued to provide an important platform for dialogue and collaboration. During the year we delivered a successful Forum event focused on patient registries, from which we produced a report and recommendations. For the first time, we ran two smaller Forum workshops bringing the community together to explore how we can strengthen advocacy for health research. A second Forum report with recommendations addressing public trust in health research, based on a 2024 Forum event, was also published.

Across the year, HRCI participated in 24 national steering groups and advisory boards spanning genetics and genomics, PPI, clinical research, mental health research and research commercialisation, alongside numerous national and international speaking engagements.

Underpinning 1: Excellent governance

Strong governance remained central to HRCI's effectiveness. The Board maintained a full cycle of meetings, alongside active sub-committees and the Irish Health Research Forum Steering Group, with refreshed committee membership across the year.

We undertook a financial audit and produced the 2024 annual accounts, while continuing to develop and refine key governance and financial policies, including updates to the reserves policy, risk register, conflict of interest procedures, crisis communications approach, PPI payment guidance and committee Terms of Reference.

Underpinning 2: Strong communications

Effective communications continued to support engagement with members and stakeholders. During 2025 we published the 2024 Annual Report, produced three newsletters, refreshed website content and strengthened our approach to capturing and reporting impact. Our LinkedIn presence grew to over 1,600 followers, and we expanded dissemination of our publications by uploading outputs to Lenus, the Irish health repository.

We also contributed to an engaged research podcast, helping to raise awareness of HRCI's work.

Underpinning 3: Funding and sustainability

Ensuring organisational sustainability remained a key priority in 2025. Throughout the year, we maintained strong financial oversight, managing budgets and financial reporting, fulfilling all reporting requirements for our key funders and meeting our commitments across all funded partnerships.

In 2025, we received grant funding of approx. €90,000 from the **Pobal Scheme to Support National Organisations (SSNO).** We have been in receipt of funding from the Pobal SSNO funding scheme since 2014. The current grant runs until end of June 2026, and we have applied for renewed 3-year funding which will cover the period from July 2026 to end of June 2029.

In 2024, we received an activity grant from the **Health Research Board (HRB)** of €90,000. We have been in receipt of HRB funding since 2017 and the current grant continues until end of June 2028.

Membership subscriptions generated approx. €55,000 in 2025, continuing a steady upward trend. This growth is driven by an increase in membership numbers and also inflation-linked fee adjustments. We have budgeted for membership income to rise to approximately €57,000 in 2026 and expect to sustain steady growth beyond then.

A 5% **Joint Funding Scheme levy** is applied to the total value of HRB funding allocated to successful research projects under the HRB-HRCI Joint Funding Scheme. We successfully ran the Joint Funding Scheme in 2024 with associated levy income of approx. €73,000 received in 2025. This scheme runs every 2 years with similar income expected in 2027.

In 2025, we received additional restricted **smaller grant income** totalling approx. €15,000. Requests for HRCI to partner on grant applications have continued to increase, with related income growing year on year. We have budgeted €29,000 for smaller grant income for 2026 and expect this level of income to continue through 2027 and beyond. We will evaluate future partnership requests to ensure meaningful alignment with HRCI's strategic goals while also supporting income generation.

On the expenditure side, rising costs driven by cost-of-living increases have led to higher salaries and event expenses.

Our net balance fluctuates due to the biennial nature of the joint funding scheme levy – giving an alternate profit and loss every year. Overall, our annual surplus has been on an upward trajectory.

Assets and liabilities and financial position

The net surplus for the year amounted to €33,652, (2024: -€22,031).

At the end of the year the company had assets of €319,040 (2024: €282,411) and liabilities of €29,620 (2024: €26,643). The net funds were €289,420 (2024: €255,768). Of the net funds at 31 December 2025 €0 of this is attributable to restricted funds (2024: €0).

Principal risks and uncertainties

The Directors have identified two primary risks and uncertainties facing the company: i) Funding Risk – The potential for reduced funding in the future and ii) Staffing Risk – The possibility of key personnel leaving or falling ill, leading to a loss of expertise.

To mitigate these risks, the company has implemented the following measures:

- Continuous monitoring of income streams, proactive identification of potential shortfalls, and the implementation of appropriate mitigation strategies.

- Maintaining open and regular communication with staff to identify and address concerns early.
- Encouraging collaboration and knowledge-sharing within the team to ensure continuity of operations.
- Well documented key processes and procedures which are centrally shared.

Additionally, the staff and finance committee also conduct an annual review of the risk register to assess and update risk management strategies as needed.

Future developments

The company plans to continue and expand the activities outlined above in the forthcoming years subject to satisfactory funding arrangements.

Structure, Governance and Management

The organisation is a charitable company limited by guarantee. The company does not have a share capital and consequently the liability of members is limited, subject to an undertaking by each member to contribute to the net assets or liabilities of the company on winding up such amounts as may be required not exceeding €1.27.

The charity was established under a Memorandum of Association which sets out the organisation's charitable objects and powers. The organisation operates in accordance with its Constitution (Memorandum and Articles of Association) and is governed by a Board of Directors, who are also the charity trustees. The Board meets regularly throughout the year and is responsible for the strategic direction, governance and oversight of the organisation.

Health Research Charities Ireland CLG believe good governance means being clear in our objectives, ethical and transparent in our dealings, accountable to our stakeholders and compliant with legal requirements. It is a way of working rather than a tick box exercise. It is about a commitment, from the Directors down, to operate in the best way at all times, for the benefit of all patients, member organisations and stakeholders. As an umbrella organisation for other charities, it is particularly important that Health Research Charities Ireland CLG acts as a positive example in all aspects of governance. We have built the trust of our members and funders, and we must work hard to retain that trust.

HRCI has been fully compliant with the Charities Governance Code since Oct 2019, and we strive to demonstrate an exemplary model of good governance to our members. We meet all core standards required for an organisation of our size and have also met many of the additional standards (which are optional for an organisation of our size). All governance documents are stored on a secure, online cloud storage service (Tresorit) and are available to view at any time by the HRCI Directors.

The organisation operates a documented schedule for the periodic review of its policies and procedures, with all revised policies subject to approval by the Board of Directors. The Board reviews and updates the Governance Compliance Record annually and ensures that the organisation submits its annual report to the Charities Regulator in compliance with statutory requirements.

We maintain a broad competency matrix and continually assess the competencies of our Board to ensure that all skills and experiences required to provide leadership and good governance are in place.

Subcommittees

Health Research Charities Ireland CLG has 3 subcommittees composed of HRCI directors, members and stakeholders which help guide and oversee the organisation.

i) Staff and Finance Subcommittee

The role of this committee is to consider all issues related to staff, finance and governance and where necessary to make recommendations

to the Board of HRCI. The committee meets prior to each Board meeting – 6 times per year. Key matters that can be considered by the committee include the following: Budgets and Financial statements, Recruitment, Human Resource Issues, including sensitive issues where it is inappropriate for a detailed Board discussion, Governance of HRCI, other issues of major concern to the HRCI.

The committee review staff salaries annually, taking into account benchmarking data, inflation, charity funds, and employee performance to determine fair and appropriate staff remuneration. Salary benchmarking publications, including *Pay and Benefits in the Community and Voluntary Sector* from The Wheel, are used as key inputs in these reviews.

ii) Advocacy and Communications Subcommittee.

The role of this Committee is to advise the Board on matters relating to Public Affairs, Advocacy and Communications. It contributes to the development of HRCI's Communications and Advocacy Strategy and provides guidance on initiatives that enhance the organisation's visibility and impact. The Committee also supports efforts to position HRCI as a leading contributor to health research in Ireland and to raise awareness of its benefits for patients and society.

iii) HRCI Appointments Subcommittee

The HRCI Appointments Committee is responsible for recommending the appointment of new directors to the Board and advising on the appointment of the HRCI Chair, members of Board subcommittees and the Chair of the Irish Health Research Forum Steering Group. The Committee operates in line with HRCI's governance framework and policies. Recommendations are actioned by the HRCI Chair and CEO, and where appropriate may be referred to the Board or relevant sub-committees for consideration prior to implementation.

Reserves

The Board has established a reserves policy requiring that reserves be held in a readily realisable form and maintained at a level sufficient to enable HRCI's core activities to continue during a period of unforeseen difficulty.

The required level of reserves is calculated with reference to the risks identified in the HRCI risk register, including the possibility that income and expenditure levels may differ from those budgeted.

At the beginning of 2025, the Board agreed that unrestricted reserves should be maintained at a level equivalent to nine months of operational costs. These costs include staff salaries, rent, and other core operational expenses such as IT and HR support, insurance, payroll, and audit fees. This nine-month reserve requirement equates to €218,000.

Attendance at Board meetings:

The HRCI Board of directors met five times in 2025. Attendance at these meetings by Board members is indicated by a tick in the following table:

Name	13 Feb	2 Apr	10 Jun	11 Sep	3 Dec
Jonathan O'Connell		√		√	√
Laura Brady*	√				
Sinéad Hickey	√		√	√	√
Frances Drummond	√	√	√	√	√
Michael Walsh*	√	√	√		
Bernadette Rock	√	√	√	√	√
Brian Lynch	√	√	√	√	√
Lesley O'Hara	√		√	√	√
Niamh Gavin	√	√	√	√	√
Claire Kilty	√	√		√	
Sarah Tecklenborg	√	√	√	√	√
*Resigned 10 June 2025					

Accounting records

The measures taken by the directors to secure compliance with the requirements of sections 281 to 285 of the Companies Act 2014 with regard to the keeping of accounting records are the implementation of necessary policies and procedures for recording transactions, the employment of competent accounting personnel with appropriate expertise and the provision of adequate resources to the financial function. The accounting records of the company are located at the registered office.

Relevant audit information

In the case of each of the persons who are directors at the time this report is approved in accordance with section 332 of Companies Act 2014:

- so far as each director is aware, there is no relevant audit information of which the company's statutory auditors are unaware, and
- each director has taken all the steps that they ought to have taken as a director in order to make themselves aware of any relevant audit information and to establish that the company's statutory auditors are aware of that information.

Auditors

In accordance with Section 383 (2) of Companies Act 2014, the auditors, McCloskey & Co, have indicated their willingness to continue in office.

This report was approved by the Board of directors on 15 April 2026 and signed on behalf of the Board by:

Brian Lynch
Director

Nikki Dunne
Director

Directors Responsibilities statement

The directors are responsible for preparing the Directors' Report and the financial statements in accordance with Irish law and regulations.

Irish Company law requires the directors to prepare financial statements for each financial year. Under the law the directors have elected to prepare the financial statements in accordance with Companies Act 2014 and accounting standards issued by the Financial Reporting Council and promulgated by Chartered Accountants Ireland including FRS 102 The Financial Reporting Standard applicable in the UK and Ireland (Generally Accepted Accounting Practice in Ireland) as modified by the Statement of Recommended Practice "Accounting and Reporting by Charities" effective 1 January 2019. Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the assets, liabilities and financial position of the company as to the financial year end and of the profit or loss of the company for the financial year and otherwise comply with the Companies Act 2014.

In preparing these financial statements, the directors are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and accounting estimates that are reasonable and prudent;
- state whether the financial statements have been prepared in accordance with applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company, enable at any time the assets liabilities, financial position and profit or loss of the company to be determined with reasonable accuracy, enable them to ensure that the financial statements and directors' report comply with the Companies Act 2014 and enable the financial statements to be audited. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The directors are responsible for the maintenance and integrity of the corporate and financial information included on the company's website. Legislation in the Republic of Ireland governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Independent Auditor's report to the members

Opinion

We have audited the financial statements of Health Research Charities Ireland CLG (the 'company') for the year ended 31 December 2025 which comprise the Statement of Financial Activities, the Balance Sheet and notes to the financial statements, including a summary of significant accounting policies set out in note 3. The financial reporting framework that has been applied in their preparation is applicable Irish law and Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland as modified by the Statement of Recommended Practice "Accounting and Reporting by Charities" effective 1 January 2019.

In our opinion, the financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31 December 2025 and of its net income for the year then ended;
- have been properly prepared in accordance with Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland; and
- have been prepared in accordance with the requirements of the Companies Act 2014.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of the financial statements in Ireland, including the Ethical Standard as issued by the Irish Auditing and Accounting Service Authority ("IAASA") Ethical Standard and we have fulfilled our other ethical responsibilities in accordance with these requirements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

As a small entity under the provisions of the IAASA Ethical Standard we engage our auditor to provide basic bookkeeping and accounts preparation.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Company's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the directors' report, other than the financial statements and our auditor's report thereon. The directors are responsible for the other information. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated.

If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by Companies Act 2014

In our opinion, based on the work undertaken in the course of the audit:

- we have obtained all the information and explanations which we consider necessary for the purposes of our audit;
- the accounting records of the Company were sufficient to permit the financial statements to be readily and properly audited;
- the financial statements are in agreement with the accounting records;
- the information given in the Directors' Report is consistent with the financial statements; and
- the Directors' Report has been prepared in accordance with the Companies Act 2014.

Matters on which we are required to report by exception

Based on the knowledge and understanding of the Company and its environment obtained in the course of the audit, we have not identified any material misstatements in the directors' report.

The Companies Act 2014 requires us to report to you if, in our opinion, the disclosures of directors' remuneration and transactions required by sections 305 to 312 of the Act are not made.

We have nothing to report in this regard.

Responsibilities of directors for the financial statements

As explained more fully in the Directors' Responsibilities Statement set out on page 6, the directors are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the directors determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the directors are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the directors either intend to liquidate the company or to cease operations or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the IAASA website at: http://www.iaasa.ie/getmedia/b2389013-1cf6-458b-9b8f-a98202dc9c3a/Description_of_auditors_responsiblities_for_audit.pdf. This description forms part of our audit report.

The purpose of our audit work and to whom we owe our responsibilities

This report is made solely to the company's members as a body in accordance with Section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters that we are required to state to them in the audit report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company or the company's members as a body for our audit work, for this report, or for the opinions we have formed.

For and on behalf of

McCloskey & Co
Chartered Accountants & Statutory Auditor

Workhub
51 Bracken Road
Sandyford Business Park
Dublin 18
D18 CV48

Date: 15 April 2026

Statement of financial activities

Health Research Charities Ireland CLG

(A Company Limited by Guarantee and not having Share Capital)

Year ended 31 December 2025

	Unrestricted funds 2025	Restricted funds 2025	Total 2025	Unrestricted funds 2024	Restricted funds 2024	Total 2024
Incoming resources:						
Membership and subscriptions	€55,232	€0	€55,232	€49,613	€0	€49,613
5% Levy on the Joint Funding Scheme	€73,684	€0	€73,684	€0	€0	€0
HRB funding	€0	€90,007	€90,007	€0	€82,500	€82,500
SSNO Project - Pobal funding	€0	€90,826	€90,826	€0	€91,015	€91,015
Corporate Support	€0	€0	€0	€0	€5,000	€5,000
Other income and awards	€2,873	€15,546	€18,419	€6,332	€27,312	€33,644
	€131,789	€196,379	€328,168	€55,945	€205,827	€261,772
Resources expended:						
Programme expenses	€0	€34,538	€34,538	€0	€93,712	€93,712
Operational expenses	€98,137	€161,841	€259,978	€77,976	€112,115	€190,091
	€98,137	€196,379	€294,516	€77,976	€205,827	€283,803
Net movements in funds for the year	**€33,652**	**€0**	**€33,652**	**(€22,031)**	**€0**	**(€22,031)**
Reconciliation of funds						
Balances brought forward at 1 January 2025	€255,768	€0	€255,768	€277,799	€0	€277,799
Transfer between funds	€0	€0	€0	€0	€0	€0
Balances carried forward at 31 December 2025	**€289,420**	**€0**	**€289,420**	**€255,768**	**€0**	**€255,768**

A separate statement of total recognised gains and losses is not required as there are no recognised gains or losses other than the surplus or deficit for the above two financial years.

Balance sheet

Health Research Charities Ireland CLG

(A Company Limited by Guarantee and not having Share Capital)

Year ended 31 December 2025

	2025		2024	
	€	€	€	€
Current assets				
Debtors	2,436		2,331	
Cash at bank and in hand	316,604		280,080	
	319,040		282,411	
Creditors: amounts falling due within one year	(29,620)		(26,643)	
Net current assets		289,420		255,768
Total assets less current liabilities		289,420		255,768
Net assets		289,420		**255,768**
Capital and reserves				
Unrestricted funds		289,420		255,768
Members funds		**289,420**		**255,768**

The financial statements were approved by the board of directors on 15 April 2026 and signed on behalf of the board by:

Brian Lynch
Director

Nikki Dunne
Director

Health Research Charities Ireland

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