Health Research Charities Ireland

HRCI Annual Report
2019

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"Looking back on the year from the perspective of 2020, as we live through a pandemic, we are delighted that we pushed forward on so many fronts."

A message from the CEO and Chairperson

2019 was an activity-filled year for HRCI and one that we are very proud of. Being our 21st year, we were determined to use the occasion to both celebrate past achievements and also to focus on ensuring a strong and valuable organisation into the future.

Central to celebrating the past achievements of the HRCI community was our conference in September. At this event we highlighted the incredible work undertaken by our member organisations, through posters and talks. In a particular personal highlight for us both, we brought together all previous and current Chairs of the organisation to share the story of the evolution of HRCI with attendees and to discuss its role into the future.

A central plank of our focus on the future was the launch of a new name and a new look for HRCI, which we hope more truly reflect our activities. The publication of a position paper, entitled 'Research for a Healthier Ireland', provided a very useful platform for engaging with politicians on the topic of health research, most visibly in the form of a discussion panel with political spokespeople for health, at our conference. We also invested energy in the development of a new strategy, to guide us in our mission of leading a vibrant, impactful and patient-led network of Irish health research charities through 2020 to 2023.

Over the year, we undertook many successful events and activities relating to our core activities of the Joint Funding Scheme (which we run in partnership with the Health Research Board), the Irish Health Research Forum and our support for Patient and Public Involvement (PPI) in research. We encourage you to glance through the following pages to see what we got up to and perhaps to engage with us on some of our activities.

Looking back on the year from the perspective of 2020, as we live through a pandemic, we are delighted that we pushed forward on so many fronts. The importance of health research to society has become much more widely evident, as health researchers in Ireland and all over the world, work to offer desperately needed solutions to the challenges of COVID-19. We will continue to build on the work undertaken in 2019 to highlight the role of health research charities, who have a deep understanding of the potential of research for all aspects of human health and a very valuable role to play.

A huge thank you to our Board, staff and all our member organisations for your many, many contributions to the successes of 2019.

Dr Avril Kennan
CEO, Health Research Charities Ireland

Suzanne McCormack
Chairperson, Health Research Charities Ireland

About HRCI

Health Research Charities Ireland (HRCI), known as the Medical Research Charities Group (MRCG) for much of 2019, is the national umbrella organisation of charities active in medical and health research, together representing over 1 million Irish patients. Through support and advocacy, we represent the joint interests of our members, working to improve health and prevent illness through research.

We facilitate access to research funding for our members through the Joint Funding Scheme, in partnership with the Health Research Board. We also fund and manage the Irish Health Research Forum, bringing together key stakeholders, to improve health research in Ireland.

Together our members make a very significant investment in health research. With addition to providing funding, they increase the quality and quantity of research in a myriad of ways, including through ensuring its relevance to patients, hosting research conferences, supporting research infrastructure such as patient registries, helping to ensure patient impact from research and communicating research developments to the public.

Our Vision 2016 - 2019

HRCI will provide a leading influence across the medical research community, promoting the full spectrum of high-quality health and medical research. HRCI believes that patient organisations should champion and stimulate the medical research critically needed by patients and their families. It will provide the intellectual and practical leadership to support and ensure the impact of charities in Ireland engaged in medical research.

Our Strategic Goals 2016 - 2019

HRCI has identified four goals for achieving our vision:

1.
Make Ireland a world-class medical research environment

2.
Ensure the full funding of medical research

3.
Communicate the value of medical research

4.
Support members in increasing capacity to actively contribute to medical research.

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

In 2019, the HRCI directors and staff worked, in consultation with our members, to develop a new strategy to guide us over the coming three years. Our new ***2020-2023 strategy*** is available on our website and reflects our intention to be responsive, collaborative and ambitious in our work.

Our impact in numbers

HRCI members in 2019

In 2019 HRCI welcomed 6 new members* to bring the total number of patient organisations represented to 39. We were delighted to also introduce an Associate membership option for the first time.

Full Members

All Ireland Institute for Hospice and Palliative Care (AIIHPC)
Alpha One Foundation
Alzheimer Society of Ireland
Arthritis Ireland
Breakthrough Cancer Research
Central Remedial Clinic
*CARD - Centre for Arthritis and Rheumatic Diseases Ireland
*CFNCRF - Conor Foley Neuroblastoma Cancer Research Foundation
CLAPAI - Cleft Lip and Palate Association of Ireland
Croí West of Ireland Cardiac Foundation
Cystic Fibrosis Ireland
*Cystic Fibrosis Registry of Ireland
Cystinosis Ireland
DEBRA Ireland
Diabetes Ireland Research Alliance
Duchenne Ireland
Dystonia Ireland
Epilepsy Ireland
*Family Carers Ireland
Fighting Blindness
Friends of the Coombe
Irish Cancer Society
Irish Heart
Irish Motor Neurone Disease Research Foundation
Irish Nephrology Society
Irish Thoracic Society
MS Ireland
MSD Action Foundation
Muscular Dystrophy Ireland
National Children's Research Centre
*Rett Syndrome Association of Ireland
Royal Victoria Eye and Ear Research Foundation
St John of God Research Foundation
St. Patrick's University Hospital
St Vincent's Anaesthesia Foundation
Temple Street Foundation
The Heartbeat Trust
The Rotunda Foundation

Associate Members

*22Q11 Ireland Support Group

Member's Story: DEBRA Ireland

Being a member of HRCI has been invaluable to DEBRA Ireland. As the Research Manager in a small rare disease charity, having access to the network of research charities and the guides and workshops through HRCI has been priceless.

I was delighted to become a member of the Board of Directors in 2019. This happened just in time to celebrate HRCI's 21st birthday, **The MRCG at 21: Looking to the Future of Health Research**, where we and other members highlighted our work, exhibited the benefits of HRCI to our organisations and celebrated the launch of HRCI's new name and branding.

Personally, when I joined the charity sector three years ago, HRCI afforded me the tools I needed to hit the ground running. Of particular value to me was participation in the 2018 workshop and subsequent guidance on Nuts and Bolts of Patient Registries. This gave me the foundations and contacts I needed to drive the development of an Irish and international patient registry for people living with epidermolysis bullosa (EB).

HRCI has guided me on how to undertake patient and public involvement (PPI) in research over the past couple of years through my membership of the PPI Shared Learning Group, where we can discuss successes and challenges with PPI and learn how to build effective strategies around PPI for our organisations. I was delighted to participate in the development of the Toolkit for involving patients and public in health research, over the course of 2019. This has helped me to engage EB (epidermolysis bullosa) patients and researchers in PPI.

It has been great to be able to share DEBRA Ireland's learnings and experience with other research charities through HRCI. In 2019, we contributed to the 'Evidence for Advocacy' workshop, presenting on how we have utilised research to achieve medical service expansion for those with EB. DEBRA's Advocacy Manager, Fiona Aherne, is a member of the Advocacy and Communications Committee and co-authored the guide arising from the workshop. This guide was presented at the EB World Congress and has since been used internationally by other DEBRAs to assist in devising their own advocacy strategy. Fiona also sits on the Rare Disease taskforce which is convened by HCRI. Membership of this dynamic taskforce is vital to communicating the needs of the patient organisation and more importantly, the members they support, to policymakers.

HRCI's ability to translate research in an accessible format is one of its key features. It ensures all events are aligned with the challenges facing its members which further solidifies their position and contribution to the rare disease charity landscape. Never before has this accessibility been more important.

I look forward to new opportunities working with the community of health research charities under the umbrella of HRCI as it continues its mission to lead a vibrant, impactful and patient-led network of Irish health research charities.

Sinéad Hickey
Research Manager,
DEBRA Ireland

Achievements and performance

Excellent progress has been made against the organisation's strategic aims, as laid out in HRCI's strategy 2016-2019. Existing HRCI activities were continued and expanded upon and new areas of activity were developed. Our 2019 activities are outlined in the following sections.

Supporting our Members

Implementing strategic aim 4:

We support our members on an on-going basis in response to their individual needs and 2019 was no exception. Our Board and member meetings are an integral part of our aim to provide opportunities for our members to come together to share experiences, discuss challenges and learn from one another. A highlight of our meetings is the round table research information exchange which sees members share what their organisations are working on. Many collaborations have developed between members as a result of these information exchanges. This year we were delighted to welcome the following guest speakers to join us at our Board and Member meetings:

- **Dr Ana Terres**, Head of Research and Development and Assistant National Director, HSE, to speak about the HSE's action plan for research.
- HRB CEO, **Dr Darrin Morrisey** and Head of Pre-Award, **Dr Anne Cody** to present on the Joint Funding Scheme
- **David Murphy**, Assistant Commissioner, Consultation Section, Health and Voluntary Sectors, Data Protection Commission.

Dr Ana Terres (in red) presenting at HRCI Board meeting

HRCI conference

In September we held a HRCI conference/21st birthday celebration for the organisation. To celebrate the success of the organisation over 21 years, we facilitated a panel discussion of the current and former Chairs, to discuss the evolution of HRCI and to look to the future of health research charities in Ireland. We used the opportunity to highlight the work of our members through talks and posters. Three HRCI members presented (Dr Mary Rabbitte, All Ireland Institute of Hospice and Palliative Care (AIIHPC); Prof Mark Little, Irish Kidney Association and Dr Laura O'Philbin, Alzheimers Society) and 17 member organisations displayed a poster on their research achievements and stating their hopes for collaboration with researchers and other charities.

John McCormack; Former Chair, Suzanne McCormack; Current HRCI Chair, Michael Griffith; Co-Founder and Former Chair, Dr Avril Kennan; HRCI CEO and Philip Watt; Former Chair.

Member posters at the HRCI conference

Survey of HRCI Members

In 2019, as part of our 2020 – 2023 strategy development, we undertook a survey of members to better understand their research activities, the issues of importance to them and how to best support them.

The survey allowed us to capture some data for the first time, on the amount of funding our member organisations invest in research. While not all provided this information, the results revealed that in 2018, 11.3 million was invested in research by 18 of our member organisations. While all of the 23 of the responding organisations invest funding in research, the results also showed that many are investing in internal and external research staff, research infrastructure and in Patient and Public Involvement (PPI) activities.

We received very strong endorsement for our proposed priority areas of work and advocacy focuses, which, together with member suggestions, have helped to guide the development of our 2020-23 strategy.

A word cloud depicting member responses to a survey question asking what they value about HRCI.

Supporting the use of Evidence for Advocacy Purposes

On 30 May 2019, a group of patient-focused organisations and other interested parties attended Health Research Charities Ireland's 'Evidence for Advocacy' seminar. They heard diverse perspectives from experts in research, policy and public relations (PR) and were also presented with case studies from a number of charities sharing refreshingly honest accounts of their experiences.

By focusing on advocacy through a research lens, the event highlighted the power of taking an evidence-informed approach to support advocacy campaigns and to guide efforts to improve health. A publication entitled ***Evidence for Advocacy: A Practical Guide - Guidance on the generation and use of evidence in charity advocacy campaigns*** was published following the seminar.

HRCI members and staff launching the 'Evidence for Advocacy: A Practical Guide'

The guide draws on the information presented by the speakers, contributions from the floor, as well as the expertise of the authors (Brian Lynch, Head of Communications and Advocacy, Arthritis Ireland; Caitríona Dunne, Head of Advocacy, Fighting Blindness; Fiona Aherne, Advocacy and Policy Manager, DEBRA Ireland & Avril Kennan, CEO, Health Research Charities Ireland). It focuses on gathering and generating evidence, using evidence to inform policy and the media as an advocacy tool. We are very grateful to all who contributed to both the event and the guide.

The HRCI/HRB Joint Funding Scheme

Implementing strategic aim 2 and 4

This innovative scheme allows the co-funding of research by HRCI members and the Health Research Board (HRB). Unlike any other scheme in Ireland, it is open to all types of health research, for all conditions. While no differentiation is made between charities or disease areas, the scheme has been particularly beneficial for health conditions where research may be limited, such as is the case with rare diseases.

To date there have been 9 funding rounds and 124 awards made, with approximately €12.5m each of HRB and charity funding dispersed over that time. 34 separate charities have had projects funded through the scheme. Currently there is a €1 million/year allocation per year from the HRB, which is matched by the charities. The majority of projects funded to date are in the broad area of applied biomedical research but projects in clinical, population health, health services and basic research have been funded also.

In addition to the obvious benefits of sharing the costs of research, the partnership with the HRB helps to build research capacity in Irish research charities and to ensure that their research processes are to a high standard. The scheme is also a shining light for PPI in health research.

Round 10 of the HRCI/HRB Joint Funding Scheme opened on October 1st, 2019. Members were asked to share their calls for research projects with HRCI and we actively disseminated them with the health research community. Fifteen member organisations attended an information session on the JFS hosted by HRB and HRCI in September. As ever, the Research Manager provided one-to-one support to many members and advice to researchers on getting involved with the Scheme. Successful awards will be announced in 2020.

HRCI Research Manager, Michelle Gardner, presents to HRCI members at a HRB-led information session on the Joint Funding Scheme

The Irish Health Research Forum

Implementing strategic aim 1

HRCI manages the IHRF, a partnership of organisations and stakeholders that aims to positively influence health research in Ireland. The Forum considers key health research issues and identifies constructive solutions at twice yearly meetings. It is nationally recognised for the quality of its events and the diversity of stakeholders it attracts. ***See more here.*** The IHRF Steering Group comprises of stakeholders with significant profile in health research and facilitates a coordinated approach to positively influencing the health research environment in Ireland. In 2019 the membership included representatives of the Science Foundation Ireland, Health Service Executive, Cancer Trials Ireland, National Children's Research Centre, Irish Research Nurses Network, the Mater Hospital, the Institute of Public Health, the Irish Research Staff Association, HRB-Clinical Research Coordination Ireland, the Irish Research Council, Scipol, patient representatives and HRCI, along with the Health Research Board attending as observers.

David Murphy,
Dr Emily Vereker,
Dr Darrin Morrissey

Event: **Data Protection and the Health Research Regulations - Finding a Way Forward**

Following our IHRF event in November 2018, on data protection and health research legislation, in May 2019 we once again gathered together a large group of people with an interest in health research, to address this highly relevant theme. It was, as ever, our aim to have constructive and inclusive discussion at the Forum event. We strongly believe in the value of creating a space where all voices can be heard in a respectful environment.

We were pleased at the solution-focused nature of the discussions and also with the diversity of the attendees e.g. patient-focused organisations made up almost 20% of an audience that also included researchers, legal experts, data protection officers, funders, policy makers etc. Caitríona Dunne (Fighting Blindness & IHRF Steering Group member), Suzanne Bracken (Clinical Research Development Ireland), Teresa Maguire (Department of Health), David Murphy (Data Protection Commission), Emily Vereker (Manager of the Consent Declaration Committee), Darrin Morrissey (HRB) and Gerry McElvaney (Irish Academy of Medical Sciences) all spoke at the event. The discussion groups involving all attendees proved very useful and popular and enabled us to develop ***a recommendation-focused report***.

Prof Brendan Buckley

Group discussion

Feedback from attendees at the IHRF

Dr Avril Kennan, Dr Suzanne Bracken, Prof Gerry McElvaney, Caitriona Dunne & Dr Teresa Maguire

Feedback from attendees at the IHRF

Today's forum was invaluable to my work as a date protection practitioner working to support and advise researchers. This event and the work of the IHRF is an excellent opportunity for practitioners and researchers to explore the nexus where research, date protection and ethics meet. Thank you. **Joan O'Connell Data Protection Coordinator, DCU**

Excellent event as always discussing relevant topics. Great to have such a mixed group of people around the table! **Niamh Clarke, Research Coordinator, St James' Hospital and Trinity College Dublin**

Collaborative, diverse and interdisciplinary forum that delivers events that focus on solutions to ensure health research improves quality of life. **Mary Rabbitte, Research Programme Manager, All Ireland Institute of Hospice and Palliative Care**

Another excellent event by the MRCG (HRCI) keeping the patient at the forefront of its discussions and continuing to work consistently towards the realisation of the positive effects of health research for the patients.
Anne Lawlor, Chairperson, 22Q11 Ireland

Provides an excellent forum for discussion/ information sharing. **Marion Rowland, Lecturer in Clinical Research, UCD**

The IHRF workshop events demonstrate the value of collaboration and consultation in relation to Health Research Regulation and direction. **Dr Louise Hopper, Assistant Professor (Psychology), DCU**

Group discussions

Event: **Working Across Health Services & Academia – Challenges and Solutions for Health Research**

The second Forum meeting of 2019, in November, focused on the interface between health services and academia. Attendees heard from Professor Joe Eustace, Chairperson of the HRB Clinical Research Coordination Ireland (CRCI) Senior Management Team; Dr Ana Terres, Assistant National Director, Head of Research and Development, the Health Service Executive; Dr Pat O'Mahony, Chief Executive, Clinical Research Development Ireland; Avril Daly, Patient Representative, VP of EURORDIS and CEO Retina International; Dr Fionnuala Keane; Chief Operating Officer, HRB-CRCI and Prof Owen Smith; Professor of Paediatric & Adolescent Medicine, University College Dublin, Consultant Paediatric Haematologist at Our Lady's Children's Hospital Crumlin and Chief Academic Lead, The Children's Hospital Group.

The event featured eight discussion groups who worked together to identify the challenges and potential solutions to a number of topics. The discussions among the groups and with the expert panel were very fruitful, highlight a number of key areas where progress could be made in improving how academia and health services work together to progress health research. The outcomes from the day, together with input from the IHRF Steering Group, were developed into over-arching ***IHRF report***, including six recommendations related to this this topic.

Dr Pat O'Mahony, Dr Fionnuala Keane, Prof Owen Smith & Avril Daly

Dr Jacinta Kelly & Prof Brendan Buckley

Feedback from attendees at the IHRF

Great to see hope, confidence, motivation and collective expertise in action in the room. Anything and everything appear possible! **Goretti Brady, Operations Manager, Health Research Institute University of Limerick**

I have attended HRCI events in the last few years. I found them very well structured with wisely selected, relevant topics that create a genuine atmosphere of peer learning/ collaboration/reflection and open dialogue. I believe this is the result of careful/detailed organisation done by HRCI. Thank you for this opportunity to participate/attend this event. **Aranzazu Bartolome, Research Admin Coordinator, CHI, Temple Street**

The only Irish group bringing all research groups together with patients on an equal footing. They get research. **Anon**

This excellent event allowed various stakeholders to bring their very valuable opinions towards contributing to the development of an excellent and coordinated national health research system. More funding is urgently needed in order to equip hospitals, higher education institutions and the HSE to make this an operational reality. **Dr Geraldine Canny, Head of the Irish Marie Skłodowska-Curie Office, Irish Universities Association**

IHRF bi-annual conferences are always informative and focused. The post conference report is really useful and increases the impact and reach of a half day event.

The networking opportunities and involvement of PPI is always excellent. **Mary Clare O'Hara, National Programme Manager, Research and Development, HSE**

HRCI provides an important platform for health researchers and stakeholders to share views on challenges in a solution focused manner. The secretariat of the HRCDC welcomes this platform to understand, interact and work with the health research community on health research regulation matters and consent declaration process. **Dr Emily Vereker, Programme Manager, Secretariat HRCDC**

IHRF has facilitated an important face to face between clinicians, academics, patients and policy makers at this workshop. It is only through more events/interfaces like this that the forging of meaningful links and changes in health research can happen. **Frances Drummond, Research Officer, Breakthrough Cancer Research**

Supporting Patient & Public involvement (PPI)

Implementing strategic aim 1, 3 and 4

2019 was a very busy year for PPI related activities. We strengthened and expanded the membership of our PPI Shared Learning Group, partnered on a project to develop training for members of the public getting involved in research for the first time, delivered a number of workshops and presentations and collaborated with UK charities to produce a guide on PPI in industry-led research. We continued to strongly engage with all five PPI Ignite programmes, which are designed to develop and strengthen PPI activities in research in Irish universities. We are official partners on the DCU, UL and TCD programmes and also work closely with the NUIG and UCD programmes.

PPI Shared Learning Group for HRCI members

In 2019, HRCI continued to support and grow the PPI 'Shared Learning Group', expanding it to 17 of our member organisations. The group includes charities that are at various stages of developing PPI within their organisations; ranging from those facilitating PPI in many different aspects of research, to those that have yet to take their first steps in formally involving patients. It provides an opportunity for members to support each other in their PPI activities, enables the sharing of PPI resources and allows HRCI to identify the most appropriate ways to support its members.

In response to our members frequently being asked by researchers for support with involving patients in their research, HRCI developed a template form for members to pass on to researchers to complete when submitting requests. It asks the researchers to outline their PPI plans and what they hope to achieve and has proven very useful for several of our members.

Developing PPI training for members of the public

The members of our PPI Shared Learning Group SLG have identified a strong need to provide training for Irish patients and members of the public, in order to support their first steps towards involvement in research. There are currently no other suitable training toolkits in existence. We discussed this need with TCD PPI Ignite who, in response, applied for a HRB Knowledge Exchange and Dissemination Scheme (KEDS) grant application, which we collaborated on. This application was successful and allowed the employment of a Research Assistant, Michael Foley, to lead on the project, along with covering other necessary expenses. We worked closely with Michael and UK expert Bec Hanley, over the course of 2019, to deliver three workshops for members of the Shared Learning Group and their patient/carer guests. Through these workshops we developed a shared understanding of how training for the public should be developed and delivered. Based on the outcomes of the workshops, a training toolkit is now in development.

Members of HRCI and their guests attend a workshop on PPI training

Guidance on undertaking PPI in industry-led research

HRCI also continued in a collaborative arrangement with an equivalent, but larger, UK PPI Shared Learning Group, which permits the extremely beneficial sharing of knowledge and resources between Irish and UK medical research charities. Following our participation in a workshop on PPI in Industry, led by the UK group, HRCI partnered with them to produce guidance on PPI in Industry. The ***guide*** was launched in September and focuses on how to overcome the issues that health research charities often face when encouraging or participating in industry-led PPI and offers practical advice on how to do it well. (HRCI subsequently hosted an event on this topic in early 2020).

The authors of the PPI in industry-led research at its launch in London, September 2019

PPI workshops and talks

HRCI delivered a number of PPI-related workshops and talks, including ones in the University of Limerick, Dublin City University and NUI Galway. Of particular note, was a workshop at the annual PPI in Research Conference in NUI Galway, the theme of which was 'Progressing Together'. This workshop, entitled 'Should Health Researchers be Trusted with your Data?' aimed to capture patient views on how their personal health data is protected and used for research. Caitriona Dunne of Fighting Blindness co-facilitated the workshop with Dr Avril Kennan.
A report from the event can be found here.

Dr Avril Kennan and HRCI Director, Dr Laura Brady of Fighting Blindness were invited to present on the topic of communicating and working with members of the public in health research, by DCU PPI Ignite.

Advocacy

Implementing strategic aim 1, 2 and 3

Together our members represent over 1 million Irish patients. They work relentlessly to improve the lives of the people they represent, through research. HRCI's role as an umbrella organisation makes us perfectly placed to understand their role and needs and we use this knowledge to advocate for improvements to the Irish health research environment, through working with policy makers, politicians and many other stakeholders.

Highlighting the importance of health research

2019 was a particularly strong year for HRCI Advocacy as we welcomed health spokespeople from across the political spectrum to discuss research towards a healthier Ireland at our conference and celebration of 21 years of activity. We were joined for a panel discussion by Roisin Shortall, T.D. (Social Democrats), Stephen Donnelly, TD (Fianna Fail), Louise O'Reilly, T.D. (Sinn Fein) and Senator Colm Burke (Fine Gael). This panel discussion was moderated by Jonathan McCrea, Whipsmart Media, and saw robust discussion among the panelists on the topics of investment in health research, genomics, the involvement of pharmaceutical companies in research and patient registries.

Roisin Shortall, T.D., Louise O'Reilly, T.D., Stephen Donnelly, T.D., Dr Avril Kennan and Senator Colm Burke

We also developed a position paper entitled ***'Research for a Healthier Ireland'***, highlighting five recommendations for politicians and other stakeholders which was formally launched at the HRCI Conference and subsequently widely disseminated to politicians and relevant stakeholders. The recommendations presented in the paper are as follows:

- **Recommendation 1:** Increase investment in clinical research in Ireland
- **Recommendation 2:** Undertake a national information campaign on the value of health research
- **Recommendation 3:** Establish a National Federation of Patient Registries
- **Recommendation 4:** Develop a National Genomics Strategy
- **Recommendation 5:** Support a National Engaged Research Hub

Broad Engagement

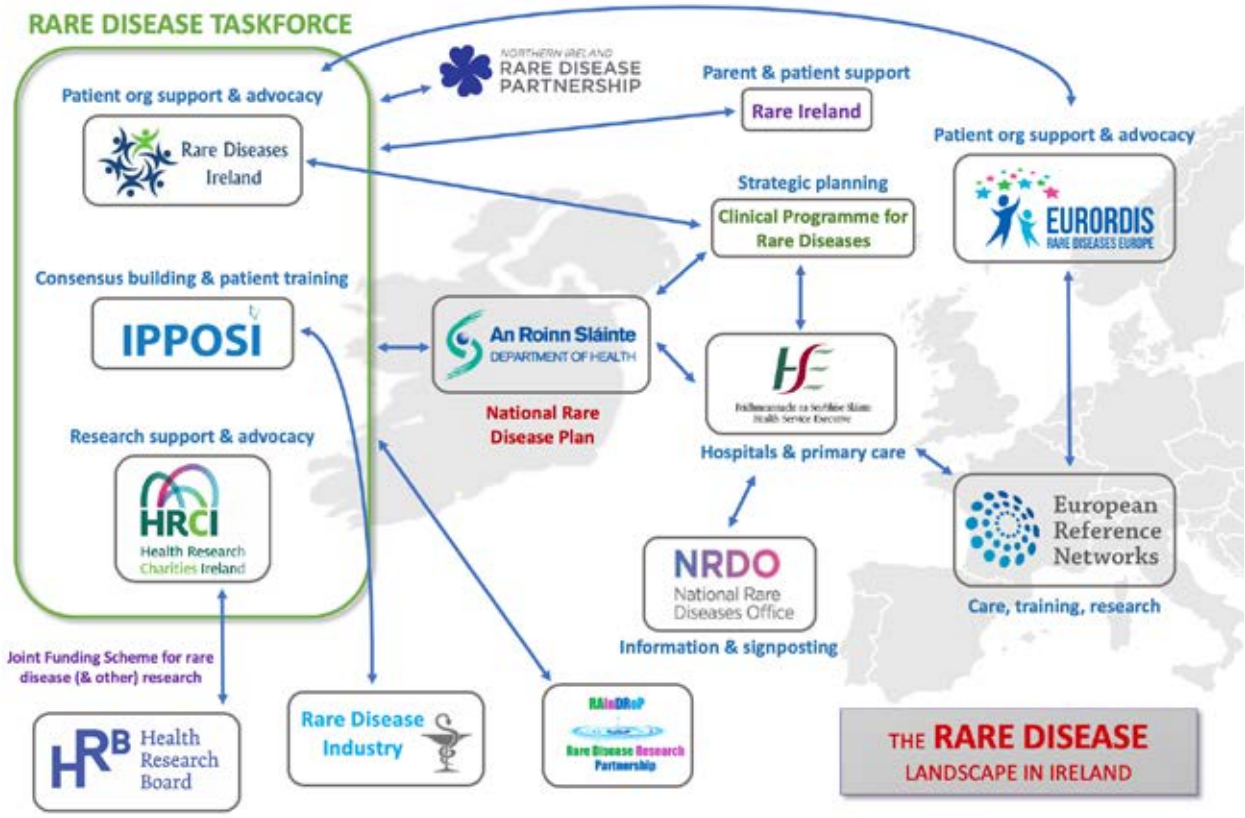
HRCI were also very active in engaging more widely with many stakeholders and partners this year. Of note, we participated in a consultation on the new Science Foundation Ireland strategy, a DCU-led event on a future strategy for nursing research, a HRB workshop on their forthcoming strategic plan, a Slaintecare Stakeholder Engagement Forum and a preliminary meeting of an Oireachtas Cross Party science committee. We also participated in an International 'Ensuring Value in Research Funders Forum' event, hosted by the HRB.

The implementation of the 2018 Health Research Regulations caused some challenges for the health research community in 2019 and so they were an additional strong focus for our advocacy. We endeavoured to seek clarity though discussions with many stakeholders, including the Data Protection Commission, the Health Research Consent Declaration Committee and the Department of Health and (as discussed above) by hosting an IHRF event on the topic.

Support for Rare Diseases

Implementing strategic aim 1 and 4

Approximately one third of HRCI members represent patients with rare diseases. While there are over 6,000 documented rare diseases, taken together it is not unusual to be affected by a rare disease. Such conditions are extremely variable in how they affect a person but people living with rare diseases have many challenges in common. These include a lack of research into their condition, lack of medical expertise, lack of treatments or cures and, often, social isolation. For these reasons, HRCI remains very committed to supporting improved research into rare diseases. In 2019, HRCI continued to provide the secretariat for the Rare Disease Taskforce, which is a partnership between HRCI, IPPOSI and Rare Diseases Ireland. On behalf of the Taskforce, HRCI also developed a much-needed stakeholder map for rare diseases in Ireland.



Rare Diseases in Ireland, Stakeholder Map 2019

Rare Disease Day 2019

HRCI worked on the Rare Disease Day 2019 event as part of the Rare Disease Taskforce subcommittee and provided considerable event management support in the leadup and on the day.

It was a successful North/South Rare Disease Day event and attracted almost 190 patients, researchers, patient organisations, carers and industry representatives. Attendees were given an update on the Rare Disease Plans by speakers from North and South of the border and heard about the patient perspective in Northern Ireland from the 10,000 Voices Campaign. The HSE's Your Voice Matters Campaign gave insights on patient experiences of health and social services in the Republic and HRCI member, DEBRA Ireland presented a patient case study outlining their efforts to identify how best to access co-ordinated services on behalf of its members.

We were also involved in planning the RAinDROP rare disease research priority-setting partnership event in UCD, as a member of the Steering Group, with Dr Avril Kennan co-hosting a workshop at the event.

Advocating for improved support for Rare Diseases

- Throughout 2019, we advocated strongly for an increased focus on the needs of rare disease patients, including the need for more research. HRCI attended numerous meetings throughout the year as part of the Rare Disease Taskforce, including those with:
- Dr Alan Smith, Deputy Chief Medical Officer, Department of Health with responsibility for the National Plan for Rare Diseases
- Eilish Hardiman, Chief Executive of the Children's Hospital Group, in relation to genetic services.
- Laura McGahey, CEO of Sláintecare to ensure the needs of rare disease patients are considered in the implementation of Sláintecare.
- Dr Colm Henry and Helen Burke (HSE) on the challenges and future plans for genomics and clinical genetic services.

Communications and PR

2019 saw the celebration of HRCI's 21st birthday which we marked with a conference where we launched a rename and rebrand. Our new name and identity was designed to create a more professional image for our organisation. In developing the new name, it was agreed that including the words 'Health and 'Irish' would be of key importance, hence the change from the Medical Research Charities Group to Health Research Charities Ireland.

The typography treatment of the logo was chosen to focus on the letters HRCI and to create a more contemporary look. In highlighting the letter 'C' we put the focus on 'Charities'.

The colour arches offer a sense of support and collaborative activity. The overlapping colours also reflect HRCI both as the umbrella body and as a charity that is connected to its members. The arches are also used as a design device to make the connection with the Irish Health Research Forum, which we rebranded at the same time, using the same arches, in order to better align it with HRCI. Members and stakeholders have been very welcoming of our rebrand and name change, and we hope it promotes our organisation as a leader in patient-focused health research.

Charities push forward health research agenda

We received strong media coverage of the conference and our Position Paper ***Research for a Healthier Ireland***, launched on the same day. The coverage included articles in the Irish Times, the Irish Independent, the Irish Examiner, Silicon Republic, the Irish Pharmacist, the Irish Medical Times, Irishhealth.com, Pharmacy News Ireland and Irish Legal News. Following the event, we were also invited to write a piece for the Medical Independent, entitled 'Charities Push Forward the Health Research Agenda'.

In line with our rebrand, we developed a new website (***www.hrci.ie***). This has allowed us to share details of our activities and to disseminate our publications and up-to-date news with greater ease. We also continue to share many updates on health research-related topics via email, blog posts, newsletters and social media. As well as communicating our own activities we place a strong focus on communicating our members and other stakeholders research news and activities.

We reached more people on Twitter than ever before in 2019 and continued to encourage the use of our hashtag, **#HealthResearchMatters**, which is frequently used by our members and supporters to facilitate us in highlighting member activities and health research news of relevance in our feed. We are strong supporters of our members and other stakeholders in our communications, particularly on social media where we champion their successes in health research and share details of research calls, job advertisements, conferences etc.

HRCI governance

To HRCI, 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 HRCI 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.

Overview of HRCI Governance:

- We are fully compliant with the **Charities Regulator Governance code**.
- Our **Board of Directors** meets six times per year to oversee all aspects of our activities and finances.
- We have a **Staff & Finance Committee** which meets six times per year.
- We have an **Advocacy and Communications Committee** which meets four times per year.
- We undergo an **independent audit** annually.
- We produce **publicly available annual accounts** which are SORP compliant (in line with the Statement of Recommended Practice, Accounting and Reporting by Charities).
- We produce in-depth **annual reports**, reviewing our achievements against our strategic goals.
- We are **compliant with all relevant legislation**, including the Charities Act 2009, the Companies Act 2014, the Lobbying Act 2015 and all HR legislation.
- At the end of 2019 we developed a strong **strategy** for 2020-23, entitled ***Together for Better Health Research***.

HRCI Structure:

HRCI Staff members at the HRCI Conference Dr Michelle Gardner, Marie Downes, Dr Avril Kennan and Linda McGrath

HRCI Board of Directors 2019

There is no remuneration of Directors and all work is done on a voluntarily basis.

The following Table shows directors year of appointment and attendance at 2019 board meetings		
Suzanne McCormack (Chair)	**2012**	6 of 6
Jonathan O'Connell (Treasurer)	**2018**	5 of 6
Jacinta Kelly (Secretary)	**2017**	3 of 6
Philip Watt	**2010**	2 of 6
Robert O'Connor	**2017**	4 of 6
Laura Brady	**2017**	6 of 6
Sinead Hickey	**2018**	4 of 6
Geraldine Kelly	**2018**	5 of 6
Michael Walsh	**2018**	3 of 6
Bernadette Rock *	**2019**	3 of 3

** Note Bernadette Rock was appointed director at the AGM in June 2019 and attended 1st meeting as a director in September 2019*

HRCI Subcommittees

The Staff and Finance Committee is a sub-committee of the Board of HRCI. The role of the committee is to consider all issues related to staff, finance and governance and to make recommendations to the Board of HRCI on these topics.

In 2019, the Staff and Finance Committee was composed of the following members:
Philip Watt - Committee Chair (CF Ireland)
Suzanne McCormack - Chair, HRCI (Irish Thoracic Society)
Jonathan O'Connell - Treasurer (Huya Biosciences)
Jacinta O'Connor - Secretary (NCRC)
Avril Kennan (HRCI)
Michael Walsh (Central Remedial Clinic)
Robert O'Connor (Irish Cancer Society)

The Advocacy and Communications Committee offers support and guidance for members as well as keeping members up to date on Ireland's advocacy landscape and providing opportunities to engage in further advocacy activities.

In 2019, the Committee was composed of the following members:
Brian Lynch - Committee Chair (Arthritis Ireland)
Suzanne McCormack (Irish Thoracic Society)
Avril Kennan (HRCI)
Caitriona Dunne - On Leave (Fighting Blindness)
Neil Ward (Fighting Blindness)
Philip Watt (CF Ireland)
Fiona Aherne (DEBRA Ireland)
Conor Culkin - Resigned (Epilepsy Ireland)
Patrick Geoghegan (Epilepsy Ireland)

Staff attending by invitation:
Linda McGrath (HRCI)

Acknowledgements for Funding

HRCI would like to thank our funders without whose support we would not have been able to function in 2019:

HRCI were successful in applying for Pobal SSNO funding 2019 - 2022. This award will support the salaries of the Events and Communications Coordinator and the Research Manager.

HRCI are in receipt of HRB multiannual funding for €75,000 per annum which will run until June 2020.

Company Details

Company Number: 377794
Charity Number: CHY 15386
Company Address:
HRCI, Digital Office Centre,
12 Camden Row,
Dublin 8, D08R9CN

Contact Details: Avril@hrci.ie

Audited Accounts

Abridged Annual accounts 2019.
Full accounts for 2019 are available on 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 2019.

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 2005293.

Directors

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:

Suzanne McCormack (Chairperson)

Jonathan O'Connell (Treasurer)

Jacinta Kelly (Secretary)

Laura Brady

Sinéad Hickey

Geraldine Kelly

Robert O'Connor

Michael Walsh

Philip Watt

Bernadette Rock
(Appointed 26 September 2019)

Principal Activities and Objectives

The main objects of the company are to inform, facilitate and support those charities in Ireland that are undertaking medical research in the development of their research function.

The activities are funded by the receipt of grants, awards, corporate support, member subscriptions and levies.

As an umbrella body, our members represent well over 1 million patients in Ireland. Health Research Charities Ireland CLG (HRCI) promotes a dynamic medical research environment in Ireland, seeking a greater understanding of how illness can be prevented, how it can be diagnosed earlier and treated more effectively, with the ultimate goal of improving the whole nation's health.

Financial review, achievements and performance

Excellent progress was made in 2019 against the HRCI strategic plan, 2016 – 2019. The organisation continued to support its members, to communicate the value of health research and took many steps to increase the quantity and quality of patient-focused health research.

Some highlights of our activities in 2019 are outlined below.

Patient and Public Involvement in Research (PPI)

PPI is incorporated into many of the goals of our strategic plan. One of our major activities in this area was our continued facilitation of a PPI Shared Learning Group for our members. The membership of this group increased from 13 to 19 organisations over the course of the year and, among those organisations, there was a notable increase in PPI activities.

We launched a guidance document for charities on PPI in industry-led research developed in partnership with a PPI Shared Learning Group of UK research charities.

We also continued and strengthened excellent partnerships with all five PPI Ignite initiatives (who support PPI in universities) in TCD, DCU, UL, NUIG and UCD. As part of these collaborations we:

- Collaborated with Trinity College PPI Ignite to hold three workshops to help shape a template training package for patients/members of the public wishing to become involved in research.
- Collaborated with National University of Ireland, Galway PPI Ignite to run a workshop capturing patient and public perspectives on the use of personal data in health research and produced an outcome report.
- Ran a workshop at the University of Limerick PPI Summer School, on what patient organisations and patients expect from PPI.

Irish Health Research Forum (IHRF)

The IHRF was established by Health Research Charities Ireland (then known as the Medical Research Charities Group) in 2014. The Forum considers key health research issues and identifies constructive solutions at twice yearly meetings. We strongly value the on-going guidance of an exceptional Steering Group of leaders in health research and the Forum is nationally recognised for the quality of its events and the diversity of stakeholders it attracts. ***See more here***.

In 2019 we ran two successful events on the topics of:

- **Data Protection and Health Research.** We published and widely disseminated a report from this event containing 18 recommendations targeted at researchers, institutions and policy makers.
- **Working Across Health Services & Academia – Challenges and Solutions for Health Research.** A report, together with recommendations, from this event is due to be published.

Both events were sold out and received excellent feedback.

Joint Funding Scheme

A new round of the Joint Funding Scheme that we manage in partnership with the Health Research Board was launched in September. ***See more here***. We were very active in promoting the scheme among the health research community through talks, engagement with university research offices and social media. We also worked hard to encourage our member organisations to participate in the scheme and to support them in numerous ways to undertake the necessary steps. We partnered with the Health Research Board (HRB) to run a workshop for our members in October 2019 on the details of the scheme and on how to undertake peer review of grant applications. Successful projects will be announced in September 2020.

Conference, Events and Publications

In May 2019 we held a seminar on the generation and use of evidence for advocacy campaigns. Following this event, we produced a publication entitled **Evidence for Advocacy: A Practical Guide**.

In September we held a HRCI conference/21st birthday celebration for the organisation. We were delighted to facilitate a panel discussion of the current and former Chairs of the organisation to discuss the evolution of HRCI and to look to the future of health research charities in Ireland. As part of the day we also facilitated a panel discussion of health spokespeople from the major political parties. Finally, we used the opportunity to highlight the work of our members through talks and posters.

In parallel with the conference we also developed a **position paper** entitled **'Research for a Healthier Ireland'**, highlighting five recommendations for politicians and other stakeholders to improve health research in Ireland. PR activities around the conference and the position paper generated 10 articles in the national press.

Other member support

We provided much one-to-one support to our members over the course of the year and provided many opportunities for them to network with each other. We also invited expert speakers to our Board and member meetings for members to learn from and share their perspectives with. These speakers included the CEO of the Health Research Board, the HSE Research and Development Lead, senior research-focused Department of Health staff and an Assistant Commissioner at the Data Protection Commission.

Organisational Rebrand

At our annual conference in September we rebranded from the MRCG (Medical Research Charites Group) to HRCI (Health Research Charities Ireland). The new name signifies that we are a national organisation and that our focus is on Health Research, which is a broader remit that the previous medical research. It was also an opportunity for a fresh new look for the charity. The rebranding incorporated new logos, print and digital company collateral and a new website.

In parallel with rebranding the organisation, we also rebranded the Irish Health Research Forum to make it more evident that it is an initiative of HRCI.

Governance

We were delighted to sign off on HRCI compliance with the Charity Regulator Governance code in October 2019, two years ahead of compliance being mandated.

Following a membership survey as well as consultation with members and other stakeholders, the Board of Directors signed off a ***new HRCI strategy 2020-2023, entitled Together for Better Health Research*** at the end of 2019.

Funding

We took a proactive approach to increasing the income for the organisation in 2019 and increased income through the following avenues:

- We were successful in our application for Pobal SSNO funding 2019- 2022 which will provide continued core funding to the organisation for another 3 years.
- We developed new membership policies which provide for two levels of membership (Associate and Full) and introduced a new fee structure for members, to be implemented from 2019 to 2022. This resulted in an increase in membership fee income from €22,100 in 2018 to €29,500 in 2019.
- We introduced an attendance charge for non-members at our events, which is helping to offset event costs.

Assets and liabilities and financial position

The financial results are set out on page 34 of the report. The retained surplus for the year amounted to €28,058, (2018: €4,840).

At the end of the year the company had assets of €205,786 (2018: €164,931) and liabilities of €34,152 (2018: €21,355). The net funds increased to €171,634 (2018: €143,576) and the directors are satisfied with the level of retained reserves at the year end. Of the net funds at 31 December 2019 €0 of this is attributable to restricted funds.

Principal risks and uncertainties

The Directors have identified that the key risks and uncertainties the company faces relate to the risk of reduced funding in the future and the potential increase in compliance requirements in accordance with company, health and safety, taxation and other legislation;

The company mitigates these risks as follows:

i. The company continually monitors the level of activity, prepares and monitors its budgets targets and projections.

ii. The company closely monitors emerging changes to regulations and legislation on an ongoing basis.

Internal control risks are minimised by the implementation of procedures for authorisation of all transactions and projects. Procedures are in place to ensure compliance with health and safety of staff.

In addition, the staff and finance committee review the risk register on an annual basis.

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 established the objects and powers of the charitable company and is governed under its Articles of Association and managed by a Board of Directors who meet several times a year.

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.

Subcommittees

Health Research Charities Ireland CLG has 2 subcommittees composed of HRCI members 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.

ii. Advocacy and Communications Subcommittee.
The role of this committee is to advise and make recommendations to the HRCI board on Public Affairs, Advocacy and Communications issues, to input into the Communications and Advocacy strategy for the HRCI going forward and to help position the HRCI as a critical player in health research in Ireland and by doing so increase the profile of medical research in Ireland.

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 he or she ought to have taken as a director in order to make himself or herself 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.

Accounts were proposed by Jonathan O'Connell (Treasurer) and seconded by Suzanne McCormack (Chairperson) at the HRCI board meeting on April 2nd,2020. They will be formally signed at the AGM on June 10th,2020. The full accounts will be available on the HRCI website.

Directors Responsibilities Statement

The directors are responsible for preparing the directors report and the financial statements in accordance with applicable 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 the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council and promulgated by the Institute of Chartered Accountants in Ireland. 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 at the financial year end date 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.

Independent Auditor's Report to the Members of Health Research Charities Ireland CLG

Opinion

We have audited the financial statements of Health Research Charities Ireland CLG (the 'company') for the year ended 31 December 2019 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 2015.

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 2019 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.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs require us to report to you where:

- the directors' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the directors have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

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.

Thomas McCloskey

For and on behalf of
McCloskey & Co
Chartered Accountants & Registered Auditor
Apex Business Centre
Blackthorn Road
Sandyford
Dublin 18

Statement of Financial Activities

As at 31 December 2019

	Unrestricted funds 2019	Restricted Funds 2019	Total 2019	Total 2018
	€	€	€	€
Incoming resources:				
Membership and subscriptions	29,549	0	29,549	22,100
5% Levy on the Joint Funding Scheme	62,777	0	62,777	31,840
Corporate sponsorship	0	2,500	2,500	5,000
HRB funding	75,000	0	75,000	75,000
SSNO Project - Pobal funding	0	85,154	85,154	85,108
Other income and awards	8,045	3,066	11,111	3,966
	175,371	90,720	266,091	223,014
Resources expended:				
Programme expenses	15,704	92,557	108,261	120,673
Operational expenses	129,772	0	129,772	97,501
	145,476	92,557	238,033	218,174
Net movements in funds for the year	**29,895**	**(1,836)**	**28,058**	**4,840**
Reconciliation of funds				
Balances brought forward at 1 January 2019	143,576	0	143,576	138,736
Transfer between funds	(1,836)	1,836	0	0
Balances carried forward at 31 December 2019	**171,635**	**(0)**	**171,634**	**143,576**

Balance Sheet

As at 31 December 2019

	2019		2018	
	€	€	€	€
Fixed assets				
Tangible assets	301		766	
		301		766
Debtors	3,626		8,534	
Cash at bank and in hand	201,859		155,631	
	205,485		164,165	
Creditors: amounts falling due within one year	(34,152)		(21,355)	
Net current assets		171,333		142,810
Total assets less current liabilities		171,634		143,576
Net assets		**171,634**		**143,576**
Capital and reserves				
Unrestricted funds		171,634		143,576
Members funds		**171,634**		**143,576**

These financial statements were approved by the board of directors on ..... and signed on .....

behalf of the board by:

Director ..... Director .....

Accounts were proposed by Jonathan O'Connell (Treasurer) and seconded by Suzanne McCormack (Chairperson) at the HRCI board meeting on April 2nd 2020. They will be formally signed at the AGM on June 10th 2020. The full accounts will be available on the HRCI website.

Health Research Charities Ireland

Digital Office Centre
12 Camden Row
Dublin 8
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