

CAVERNOMA IRELAND

ANNUAL REPORT

2025



Cavernoma
Ireland



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Introduction

This report provides an overview of our work and impact in 2025, including key updates within Cavernoma Ireland, our engagement with members, and our efforts to raise awareness of cavernoma. It highlights important moments such as Rare Disease Day, Cavernoma Awareness Month, and our collaboration with national and European partners, as well as our engagement with policymakers and the growth of our community.

It also outlines our focus for 2026, offering insight into our priorities, plans, and financial outlook. We hope this report helps members, supporters, and stakeholders better understand the work we do and the difference it makes.

About Cavernoma Ireland

Cavernoma Ireland supports people living with cavernoma in Ireland, their families, carers and supporters.

We aim to improve health, wellbeing, and quality of life by providing reliable information, peer support, advocacy and opportunities to connect with others.

Through awareness-raising and collaboration with national and international partners, we work to improve understanding of cavernoma, enhance services, and achieve better outcomes for everyone affected.



Our Team



- Sandra Phair - Roles: Trustee, Chairperson, Administrator, Treasurer, Data Protection Officer and Designated Liaison Person.
- Charlotte Cuffe - Roles: Trustee, Vice Chairperson and Science & Research Officer.
- Séamus Carroll - Roles: Trustee, Secretary and Health & Safety Officer.
- Laurence Cuffe Phd - Role: Risk Management Officer.
- Lorraine McTeigue - Role: Joint Signatory of Financial Account. Co-opted onto the committee for her expertise. She is a 'Community Development Officer' with Cavan County Local Development (CCLD).

2025 in Review

2025, our second year as a registered non-profit voluntary support group, has been a year of continued progress and impact.

We continued to engage our community through online activities, including monthly virtual Coffee & Catch-Ups, alongside an in-person event, creating valuable opportunities for connection.

We raised awareness of cavernoma, both independently and in collaboration with other organisations, while also engaging with policymakers to advocate for those affected.

Our fundraising activity has supported our continued growth and strengthened our ability to provide information, connection and support.

Online Events

We held 11 virtual “Coffee & Catch-Ups,” providing members with a welcoming space to connect, share experiences, and offer mutual support within the cavernoma community. A total of 20 people attended across the events, with some attending more than one.



Growing Our Membership

We welcomed 14 new members in 2025, bringing our total membership to 110 by the end of the year.



Rare Disease Day



#LightUp4Rare is a global Rare Disease Day initiative where buildings worldwide are illuminated to raise awareness and unite the rare disease community through a chain of lights.

Cavan Courthouse was illuminated once again, marking our sixth consecutive year of lighting the building in support of raising awareness.



Pictured here:

Our Chairperson Sandra Phair, Cllr T.P. O'Reilly Cathaoirleach Cavan County Council, Senator Pauline Tully, members of Rare Ireland and their families. Photo by Lorraine Teevan.

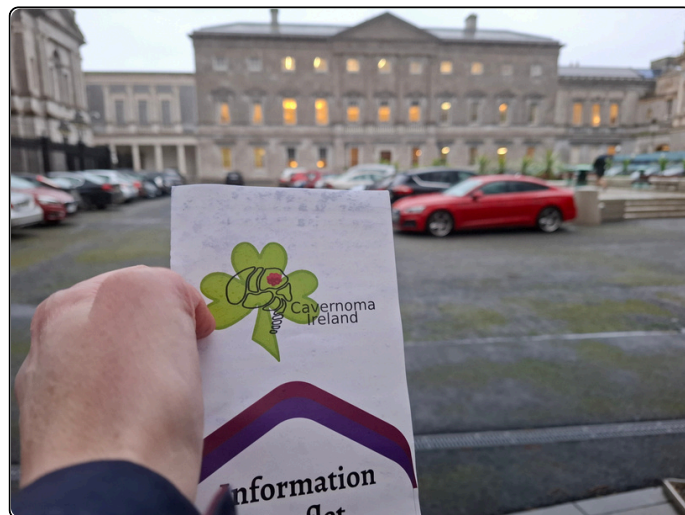
The photograph was published in The Anglo-Celt newspaper and shared across the social media platforms of Cavan County Council, Rare Ireland, Rare Diseases Ireland and Cavernoma Ireland.

Engaging with Policymakers

'All Party Group meeting on Rare Diseases'

Cavernoma Ireland, which is a member of Rare Diseases Ireland (RDI), was at the Oireachtas 'All Party Group meeting on Rare Diseases' in Leinster House, on the 26th February.

Our Chairperson Sandra Phair attended the meeting. It was attended by RDI representatives, Minister for Health Jennifer Carroll MacNeill, Deputy Pádraig O'Sullivan, and Senator Pauline Tully, as well as a number of other TDs, Senators, and patient advocates.



Leinster House Dublin

The meeting was marking Rare Disease Day by reconvening the Oireachtas All Party Group on Rare Diseases for the first time with the new Dáil. Organised by RDI.

The meeting focused on the following key areas:

- The challenges of living with a rare disease in Ireland.
- RDI's vision for the future, including the imminent publication of a new National Rare Disease Strategy.
- The opportunities for Ireland as RDI works to embed innovation at the heart of care for people living with rare diseases.



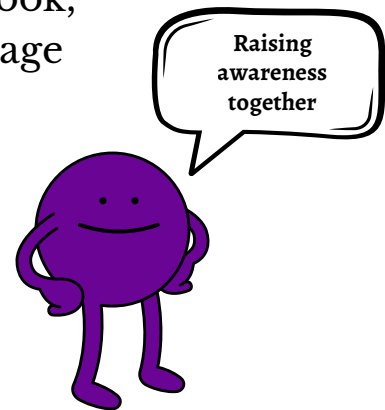
Raising Awareness

Social Media Awareness

In 2025, our Facebook page posts reached 70,888 people. Our audience on Instagram is also steadily increasing, and we continue to build and strengthen our connections on LinkedIn.

We maintain an active presence across Facebook, Instagram, LinkedIn and X, helping us to engage with a wider audience and raise awareness of cavernoma and our work.

This illustrative character is used across our social media campaigns to support and draw attention to awareness messages.



NIRDP Campaign

The Northern Ireland Rare Disease Partnership (NIRDP) raised awareness of cavernoma on the 3rd June as part of their “Rare Disease Awareness Campaign Shines a Light.”

Throughout the month of June, NIRDP highlighted a different rare disease each day, helping to raise awareness across a wide audience.

We are pleased that NIRDP now features information on cavernoma on its website.



NIRDP Facebook Post



Raising Awareness

Organisations and Groups

Throughout the year, a range of organisations and groups shared our social media posts on cavernoma, related conditions, and our events. These organisations are based in both Ireland and internationally.



Their support has significantly helped to extend our reach and raise awareness among a wider audience.

Celebrating Rare Disease Day

On Rare Disease Day, our secretary Séamus Carroll visited Lenister House while it was illuminated as part of the global #LightUp4Rare initiative.





Raising Awareness

Public Partnership Networks

Public Partnership Networks (PPNs) across Ireland shared information about cavernoma during June awareness month, in both their social media and newsletters.

PPN's are local networks of community, voluntary, environmental, and social inclusion groups in every county and city council area in Ireland. They act as a link between communities and local government, giving people a structured voice in local decision-making.



Examples of PPNs raising awareness of cavernoma during June

Cork County PPN
Newsletter

Meath PPN
Facebook Post



Health Service Executive

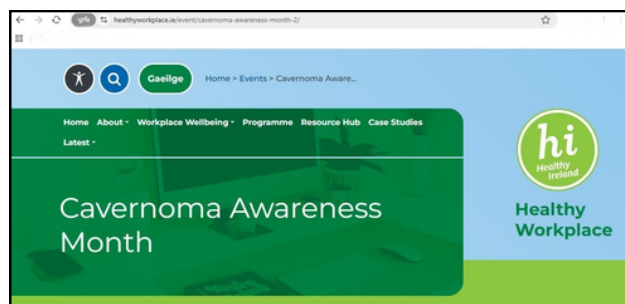
In 2025, we once again submitted our annual request to the Health Service Executive (HSE) to include Cavernoma Awareness Month in their official calendars. The HSE Awareness Calendar reaches HSE staff, healthcare professionals, and the general public across Ireland; it is available as a PDF on the HSE Library website and is widely shared on other platforms. The Healthy Workplace Ireland Calendar connects with employers, managers, HR professionals, and employees nationwide, promoting health and wellbeing initiatives.

By featuring Cavernoma Awareness Month in both calendars, we continue to raise awareness of the condition among healthcare providers, workplaces, and the wider community.

Health Information Calendar



Healthy Ireland Healthy Workplace Calendar



Annual In-Person Event



To mark Cavernoma Awareness Month, we were thrilled to host an in-person gathering on the 14th June at the Maldron Hotel in Portlaoise.

The event brought together patients, a family member, and professionals for an inspiring and informative day, featuring two guest speakers whose presentations offered valuable insights into living with brain injury and navigating the challenges of cavernoma diagnosis and treatment. Their talks sparked meaningful conversations and created a welcoming, engaging atmosphere.

Attendees left feeling informed, supported, and connected. This made the event a true highlight of the year, and we look forward to welcoming everyone to our future events.

Pictured here: Attendees at our in-person event.

Event Speakers

As part of our Annual In-Person Event, we welcomed the following speakers:

Gene Vickers – Acquired Brain Injury Ireland

Gene delivered an insightful and practical talk on living with an acquired brain injury, sharing strategies that attendees could apply in their daily lives.



Larry Cuffe

Larry shared a powerful and relatable perspective as a parent navigating cavernoma diagnosis and treatment, prompting thoughtful discussions and resonating strongly with attendees.



New Organisational Memberships



Cavernoma Ireland in 2025 became members of:

- **Vascular Voice Network**
and
- **niNCA - Northern Ireland Neurological Charities Alliance**

Vascular Voice Network is a “cross-condition initiative designed to connect charities and advocacy organisations, clinicians, researchers and system leaders around the shared goal of improving care and outcomes for people with vascular conditions.”

niNCA is “A voice for people living with a neurological condition in Northern Ireland.” They raise awareness of the needs and challenges faced by people with neurological conditions and advocate to improve local health services. Their goal is to ensure timely, accurate diagnosis and access to appropriate multidisciplinary care and support.

Cavernoma Ireland maintains membership of a range of national and international organisations across health and patient advocacy.



European Cavernoma Alliance

Cavernoma Ireland, as a member of the European Cavernoma Alliance (ECA), joined forces with fellow ECA members to support the campaign 'Important Change is Needed'.

Currently, only hereditary cavernoma is officially recognised as a rare disease, while symptomatic sporadic cavernomas, though uncommon, are not.

ECA is campaigning for recognition of symptomatic sporadic cavernoma as a rare disease.

ECA Member Organisations:

- Asociación Española de Cavernomas (Spain)
- Association sur les Cavernomes Cérébraux (France)
- Associazione Nazionale Angioma Cavernoso Cerebrale (ANACC) (Italy)
- Cavernoma Alliance UK
- Cavernoma Ireland
- Cavernoma Portugal
- Cavernous Angioma Sweden (CASE)
- Deutscher Verband für Kavernome e.V. (Germany)
- Kavernomat Suomi (Finland)
- Kavernøs Angiom Norge (KAN) (Norway)



The Campaign Video

<https://www.facebook.com/CavernomaIrelandSupport/videos/1666049677639238/>

CAUK 20th Anniversary



Cavernoma Ireland attended Cavernoma Alliance UK (CAUK) 20th Anniversary Celebration in London in October.

The event marked two decades of support, advocacy, and community.

We value our ongoing collaboration and continued work with CAUK in supporting those affected by cavernoma and advancing understanding of the condition.

Pictured here;
CAUK's Charity Manager Helen Evans, and CAUK's Founder Dr. Ian Stuart.
Cavernoma Ireland's Chairperson Sandra Phair and Vice Chair Charlotte Cuffe.

Fundraising

Climb Snowdon



Charlotte Cuffe, our Vice Chair, planned to climb Snowdon the highest mountain in Wales (1,085 metres), in support of Cavernoma Ireland. She raised €1,108.18.

Due to illness, Charlotte was unable to take part in the climb alongside a group from Cavernoma Alliance UK, but intends to complete the challenge in 2026.



Fundraising helps us continue to grow and support all of Cavernoma Ireland's work.



Our Focus for 2026

In 2026, Cavernoma Ireland will continue to build on 7 years of dedicated work supporting individuals affected by cavernoma.

Our primary focus will remain on providing vital services and raising awareness of the condition, while also supporting key research initiatives that contribute to improving lives and expanding our impact.



Our priorities for the year include:

- **Supporting Members:** Continue to provide connection and peer support through our monthly online Coffee & Catch-Up events and other engagement opportunities, ensuring members feel informed and connected.
- **Raising Awareness:** Maintain activities to increase understanding of cavernoma and related conditions at a national and international level.
- **In-Person Events:** Host opportunities for members and supporters to connect face-to-face.
- **Fundraising:** Support from fundraising helps us grow and enhance the resources and services available to everyone in our community.
- **Research Engagement:** Cavernoma Ireland will remain closely involved in the gene therapy project with Cavernoma Alliance UK, sharing our knowledge and experience of supporting people affected by cavernoma to help improve care and support. While we will not provide further funding to this project, we will continue to contribute in an advisory role.



Our Focus for 2026

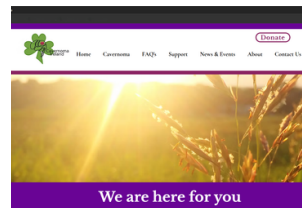
Through these activities, Cavernoma Ireland continues to make a meaningful difference for our members and the wider community, with a strong, established network across Ireland and connections with international organisations.

Financial Outlook for 2026

In the coming year, expenditure will increase as Cavernoma Ireland takes on a number of core operational costs for the first time.

New & Ongoing Core Costs

- Insurance cover is being introduced this year as a new requirement.
- Website hosting and domain registration costs will now be incurred directly by Cavernoma Ireland, as these were previously supported in-kind by a member.



Annual Event Costs

As Cavernoma Ireland's annual event returns to Dublin in 2026, costs may vary compared to previous years.

These variations are influenced by factors such as:

- Venue and event-related expenses, which may differ from 2025's location.
- The decision to host the event in Dublin, reflecting feedback from our members and expected attendance.



We are committed to managing costs effectively while ensuring the event remains accessible to all participants.

Financial Outlook for 2026

Fundraising Requirement

Fundraising directly supports:

- Core operational costs
- Insurance and website hosting
- Annual in-person event delivery



These increased costs mean that continued fundraising will be essential in 2026 to support core activities.



Financial Report 2025

Balance Brought Forward from 2024	Amount
Balance Brought Forward	€472.43
Income	Amount
Christmas Raffle 2024	€425.78
Fundraising Charlotte Cuffe 2025	€1108.18
Donations 2025	€12.00
Credit Union Share Dividend	€0.54
Total Income	€1546.50
Expenditure	Amount
Postage of Raffle Prizes	€31.85
June Event	€292.95
D.I.R.T on Dividend Credit Union	€0.17
Stationary	€4.09
Total Expenditure	€329.06
Closing Balance 2025	€1689.87

Our financial account was opened in November 2023.

2024 Christmas Raffle money raised, came into the account from iDonate in January 2025.

Contact Us



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