CAVERNOMA IRELAND

ANNUAL REPORT

2024

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www.cavernomaireland.ie

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About

Cavernoma Ireland is a voluntary support group.

The group’s mission is to help people living in Ireland who are affected by cavernoma, including friends, family, carers and professionals.

We aim to do this through support, providing information, putting members in contact with other relevant parties and hosting events.

Our goal is to raise awareness of cavernoma, and its consequences for those affected.

Management Committee

Sandra Phair - Chairperson, Admin and Treasurer.

Charlotte Cuffe - Vice Chairperson and Scientific Research Officer.

Séamus Carroll - Secretary.

Key Activities and Achievements

2024 our first as a registered voluntary support group, has been very active!

We have been in the lucky position to be involved in a wide variety of events from fundraising, raising awareness, to an in-person event.

We were awarded funding that allowed us to design and print leaflets, stickers, pens, a pop-up banner and more, while a generous donation allowed us to cover the cost of hosting our new (self-designed) website.

We held an in-person event for the first time since covid, which was a great success with interesting speakers and lots of opportunity for members to chat.

In addition we also hosted 12 online catch-up providing members the valued opportunity to connect with others affected by cavernoma.

We have been involved in novel research alongside Cavernoma Alliance UK, as well as taking part in the first European Cavernoma Patient survey published by the European Cavernoma Alliance.

Our fundraising efforts in 2024 have included a mini marathon fundraiser and our Christmas raffle, raising €512.32 in total, which will contribute to our work for the upcoming year.

Finally, our membership rose by 15 members to nearly 100 members in total! We look forward to seeing many of you at our events in 2025 and to continuing to support our members and raising awareness.

June In Person Event.


WE INVITE YOU TO ATTEND

Cavernoma Ireland Launch

Guest Speakers

Epilepsy Ireland - Geraldine Dunne

Headway Ireland - Shane Fitzgerald & Rachel Coyle

15th June

2:15pm

St. Mary's
Parish Hall
Haddington Road
Dublin 4
D04AV25

Please register to attend

Email: cavernomaireland@gmail.com

12 Monthly Online 'Coffee & Catch-Up' events.


Join Us Thursday

Coffee & Catch-Up

At 7pm via Zoom

15 New Members in 2024.

Total members at the end of year was 96.

iDonate

In February we registered with iDonate, for a fundraising donation profile.

Donations can be made to us through the fundraising platform. And fundraising pages can be set up and select Cavernoma Ireland as the cause.

https://www.idonate.ie/cause/CavernomaIreland

iDonate

https://www.idonate.ie › cause › Cavernomalreland

Cavernoma Ireland | Online Fundraising

Here For You

Cavernoma Ireland

About Cavernoma Ireland

Donations made during a month, iDonate transfers them to our financial institution the following month. The money transferred is minus iDonate's charging fee's.

Rare Disease Day: 29th February

#LightUp4Rare is a global initiative campaign on rare disease day. Buildings around the world are lit up. This helps to raise awareness of the rare disease community and uniting all of us by creating a chain of lights around the globe.

We had Cavan Court House light up. This was the 4th year we have had the building light up.

In attendance;
Sabrina Walsh.

Cavan County Cllr Trevor Smith.

Sandra Phair Cavernoma Ireland.

The Cathaoirleach of Cavan County Council, Cllr Philip Brady.

Amanda & Lorcán Connolly members of Rare Ireland.

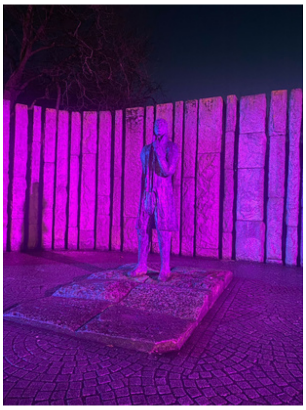
Fianna Fáil TD Brendan Smith.

The photograph was published in The Anglo Celt newspaper.

It was also posted on social media accounts of:
Cavan County Council, Fianna Fáil TD Brendan Smith,
Rare Ireland, Rare Diseases Ireland and Cavernoma Ireland.

Séamus Carroll took photographs in Dublin.
The National Concert Hall, and the 'Wolfe Tone' Statue at St. Stephens Green.

The statue photograph posted on Twitter, has had 2874 views.



Cavernoma Awareness Video

Our cavernoma awareness video was put up on our YouTube channel in February 2024.

https://www.youtube.com/watch?v=xuxKvXOcyvM

#GetRareAware Campaign

We took part in Rare Diseases Ireland's campaign - 'Get Rare Aware'. It focused on the Newborn Screening program.
"A call for urgent improvements to newborn screening".

"Get Rare Aware aims to raise awareness of rare diseases among elected representatives and highlight the challenges of living with a rare disease"

Cavernoma Ireland's logo is on the organisations supporting the campaign's poster.

We shared social media posts of the invite for people to write to their TD's, Rare Diseases Ireland's graphic posters of information and events they held.

We attended Rare Disease Ireland's online events.

June Cavernoma Awareness Month

In Person Event

On Saturday June 15th 2024 Cavernoma Ireland held an event to mark its launch and bring Cavernoma patients and careers together.

The event took place at St. Mary's Parish Church Hall on Haddington Road in Dublin.

The event featured a presentation by Geraldine Dunne from Epilepsy Ireland,

Epilepsy affects many Cavernoma patients so the subject was very relevant.

This was followed by a presentation by Shane Fitzgerald and Rachel Coyle from Headway Ireland. Headway provides services and support for those with brain injury and the presentation focused particularly on their weekly podcast. A talking heads film featuring many of those that have taken part in the podcast was shown to the audience.

The MC for the event was Charlotte Cuffe.

Sandra Phair distributed leaflets and information at the event.

Séamus Carroll introduced the new Cavernoma Ireland website.

In Person Event continued

The presentations and talks were followed by tea and cakes and an opportunity for attendees to chat to one another and generally swap stories.

The event was a great success and was enjoyed by everyone in attendance with a lot of Cavernoma related information changing hands

14th June Cavernoma Awareness Day

We launched the International Cavernoma Organisations poster, we designed.

It has been viewed by 1.2K Facebook profiles.

Grant

We are very grateful recipients of a 'Social Inclusion and Community Activation Programme'(SICAP) grant.

With the help of Cavan County Local Development(CCLD) Lorraine McTeigue Development Officer, we were awarded €638.35

This grant was for promotional materials; Leaflets, Flyers, Posters, a Pop-Up Banner, Pens, Stickers and Tablecloth.

We designed the Leaflets, Flyers and Posters ourselves. And had them professionally printed.

We launched them at our June Event.

Social Inclusion & Community Activation Programme (SICAP) 2024-2028

"This project is co-funded by the Government of Ireland and the European Union."

Rialtas na hÉireann
Government of Ireland

Arna chomhchistiú ag an Aontas Eorpach
Co-funded by the European Union

SICAP

LCDC

Cavan County Local Development

New Logo

Our new logo was designed by Hannah Cuffe.

Our main logo has the writing to one side of. the design.

We launched it in June.

Website

Our website is live.

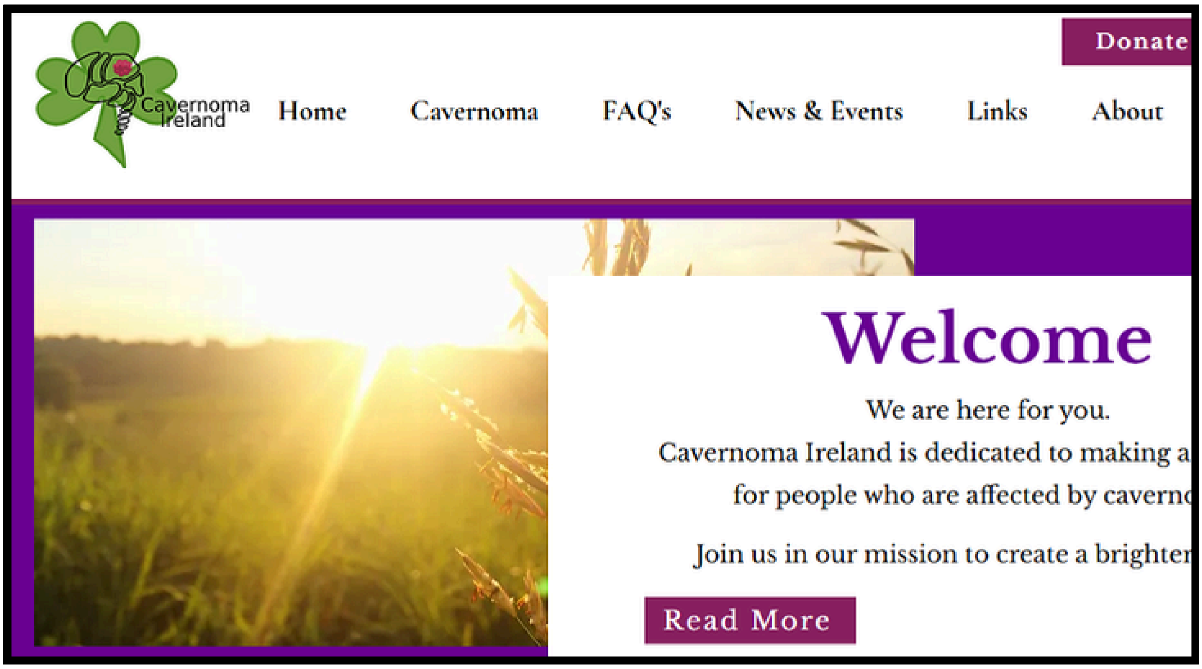
We have designed and built it ourselves.
It is a work in progress!

A generous donation has covered the cost of our website for 2 years (this includes website building software, the hosting of the website, and the domain).

The domain was purchased in February 2024.

Building of the website started in 2024.

https://www.cavernomaireland.ie



Welcome

We are here for you.

Cavernoma Ireland is dedicated to making a
for people who are affected by caverno

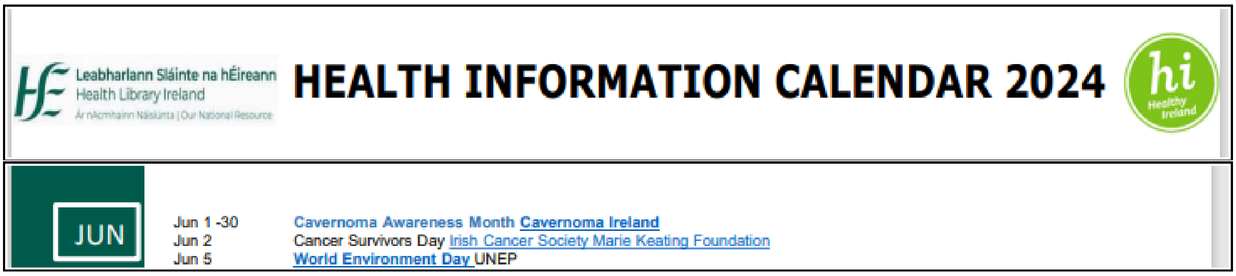
Join us in our mission to create a brighte

HSE
Cavernoma Awareness Month

We sent a request to the HSE to have ‘Cavernoma Awareness Month’ added to the HSE Calendars.

HSE (Health Service Executive)
2024 Health Information Calendar

https://hselibrary.ie/wp-content/uploads/2023/12/Health-Information-Calendar-2024.pdf



HEALTH INFORMATION CALENDAR 2024

JUN	Jun 1 -30	Cavernoma Awareness Month Cavernoma Ireland
	Jun 2	Cancer Survivors Day Irish Cancer Society Marie Keating Foundation
	Jun 5	World Environment Day UNEP

and the

Healthy Ireland Healthy Workplace website

https://healthyworkplace.ie/event/cavernoma-awareness-month/

Cavernoma Awareness Month

Healthy Ireland is the national Framework for action to improve the health and wellbeing of everyone living in Ireland.
It is a government-led initiative.

Raising Awareness

August, September and October;
Public Partnership Network’s (PPN’s) helped to raise awareness.

Public
Participation
Networks
Ireland

15 PPN's in the Republic of Ireland, put information about cavernoma and Cavernoma Ireland in their ebulletin’s and on their social media.

These bulletins are seen by their members, people/organisations that has signed up to receive their ebulletin's. Some also have them on their websites.

The awareness was spread out over the three months, as these PPN’s ebulletins are bi-monthly/monthly.

PPN's are funded by the government.
Cavernoma Ireland is a member of 9 PPN’s.

Through out the year other organisations and groups shared our social media awareness information posts about cavernoma, cavernoma related conditions, and our events.

These organisations and groups, are from Ireland and worldwide.

Research

'Novel Gene Therapy'

Cavernoma Ireland is a funding partner alongside Cavernoma Alliance UK and a philanthropist.

This is the first gene therapy research to be taking place in the UK for hereditary brain cavernoma. It started in 2024

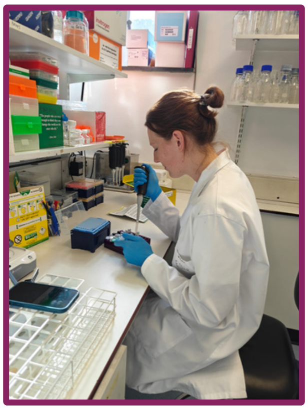
Fundraising_Cavernoma Ireland did in June 2020 for 'Research for a Cure', is going towards this research. We had a raffle and Connor McGrath did a 10K run. The money was given to Cavernoma Alliance UK (CAUK) to hold for us, as we did not have a financial account at that time.

The research will aim to gather robust data, in the hope to move closer to an alternative treatment for cavernoma.

The funding has been awarded to the UCL Institute for Women's Health, one of the world’s leading institutes for scientific research.

The research team will be led by Dr Rajvinder Karda, who specialises in the development of novel gene therapy and RNA editing treatments for early onset, incurable genetic diseases of the central and peripheral nervous system.

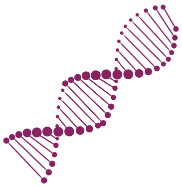
'Novel Gene Therapy' research continued



The UCL research team, will also be working in collaboration with Uppsala University and a research team led by Peetra Magnusson, a vascular biologist focusing on vascular malformations, specifically cerebral cavernous malformations (CCM).

CAUK and Cavernoma Ireland will be involved through-out the project, sharing our knowledge and experience of patient's and the end-point needed to improve care and support.

Whilst this is early stage research, with a 10 to 15 year road map before gene therapy might be available for patients, it marks an important milestone for cavernoma research.



New Members Of:

Rare Diseases Ireland

IPPOSI

Cavernoma Ireland in 2024 became members of:

- Rare Diseases Ireland

  and
- IPPOSI (Irish Platform for Patients Organisations, Science & Industry).

Rare Diseases Ireland is “a patient advocacy national alliance for voluntary groups representing people affected by or at risk of developing a rare disease.”

IPPOSI is “the collective voice of patients, science and industry in Ireland’. Their vision is to be “The patient voice is at the centre of all health policy, care, research and innovation in Ireland.”

Proud members of:

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

Rare Diseases Ireland

IPPOSI

European Cavernoma Alliance

Public Participation Network Cavan

Carlow PPN Public Participation Network

Public Participation Network Cork County

Public Participation Network Kildare

Public Participation Network Meath

Public Participation Network Monaghan

OFFALY PUBLIC PARTICIPATION NETWORK

South Dublin County Public Participation Network

Waterford Public Participation Network

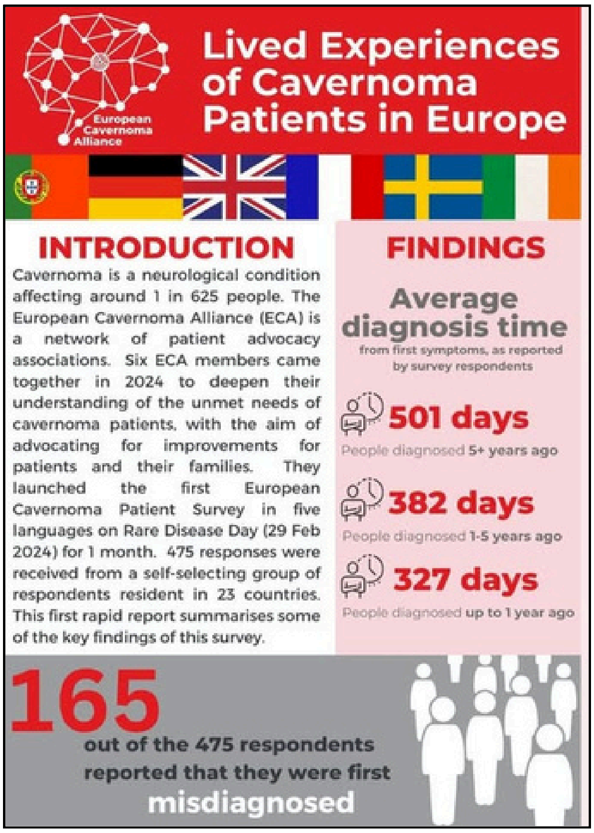
European Cavernoma Alliance

Cavernoma Ireland is an associated member of the European Cavernoma Alliance (ECA).

We took part in the 1st ‘European Cavernoma Patient’ survey. The results was published in June.

The survey’s aim was to identify the unmet needs of cavernoma patients in Europe and the comparative standards of clinical care in the different participating countries
(UK, Ireland, France, Portugal, Germany and Sweden).

This information will be used by the European Cavernoma Alliance patient organisations to advocate for better treatment options and health care services.



European Cavernoma Alliance

Lived Experiences of Cavernoma Patients in Europe

INTRODUCTION

Cavernoma is a neurological condition affecting around 1 in 625 people. The European Cavernoma Alliance (ECA) is a network of patient advocacy associations. Six ECA members came together in 2024 to deepen their understanding of the unmet needs of cavernoma patients, with the aim of advocating for improvements for patients and their families. They launched the first European Cavernoma Patient Survey in five languages on Rare Disease Day (29 Feb 2024) for 1 month. 475 responses were received from a self-selecting group of respondents resident in 23 countries. This first rapid report summarises some of the key findings of this survey.

FINDINGS

Average diagnosis time

from first symptoms, as reported by survey respondents

501 days

People diagnosed 5+ years ago

382 days

People diagnosed 1-5 years ago

327 days

People diagnosed up to 1 year ago

165

out of the 475 respondents reported that they were first **misdiagnosed**

Survey results:

https://sites.google.com/cavernostangiomsverige.org/eca/home

Fundraising

VHI Women’s Mini Marathon

Leah Cummins on the 5th June did the
VHI Women's Mini Marathon 10Km in Dublin.
Raising €100

https://www.idonate.ie/fundraiser/LeahCummins

Christmas Raffle

Cavernoma Ireland

CHRISTMAS RAFFLE

TICKETS ON SALE NOW

1ST - €100 ONE4ALL GIFT CARD
2ND - FRAMED ARCYLIC PAINTING
3RD - GOLD NECKLACE HANDCRAFTED
4TH - €50 DUNNES STORES GIFT CARD

Tickets
1 for €3 or 2 for €5

Draw 31st December

Our raffle was a great success. Raising €416.

The draw was on the 31st December 2024, the winners were randomly selected by iDonate’s ‘Pick a winner’ tool.

Prizes:
1st - €100 One4All Gift Card

2nd - Acrylic Painting Framed. 'Lemons & coffee pots'.
Painted by Hannah Cuffe

3rd - Gold Vermeil Necklace with a Chrysoprase stone.
Handcrafted by Aisling Smith

4th - €50 Dunnes Stores Gift Card

- The gift cards were donated by members.
- Hannah Cuffe donated the painting.
- Aisling Smith donated the necklace.

https://www.idonate.ie/raffle/CavernomaIrelandChristmasFundraiser

Cavernoma Ireland
Financial Report - 2024

Balance Brought Forward from 2023	**Amount**
Donation November 2019	**€70.00**
Income	**Amount**
Fundraising June 2020 - Reallocation from CAUK Accounts	€500.00
Fundraising June 2024	€96.32
Donations 2024	€347.80
Grant SICAP - For Prominal Materials	€638.35
Credit Union Share Profit	€0.31
Total Income	**€1,582.78**
Expenditure	**Amount**
June Event	€530.21
Grant SICAP - Promotional Materials	€638.35
Balance of Grant Item Purchased	€8.68
Postage	€2.80
Total Expenditure	**€1,180.04**
Closing Balance 2024	**€472.74**

Our financial account was opened in November 2023.

The Christmas Raffle funds raised, will be in 2025 financial year accounts. As iDonate will transfer any donations made in December 2024, into our financial institution account in January 2025.

Contact Us

cavernomaireland@gmail.com

www.cavernomaireland.ie

Cavernoma
Ireland