

VASCULITIS IRELAND AWARENESS

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2022

The trustees present their report with the financial statements of the charity for the year ended 31 December 2022.

OBJECTIVES AND ACTIVITIES

Objectives and aims

Purpose of charity

The purposes of the charity are:

- To provide support,
- To raise awareness and
- To improve services and care for those affected by Vasculitis, and support Vasculitis research.
- To liaise with medical professionals, researchers and pharmaceutical companies in advancing a better understanding of vasculitis and improved outcomes for patients.

In furtherance of the above objectives the charity may:

- Provide information, advice and guidance to people affected by any of the Vasculitis diseases.
- Hold “coffee and chat” meetings
- Organise meetings (open to anyone with a chronic illness) around topical issues such as Welfare Reform etc.
- Organise and run fundraising events
- Hold annual conferences
- Provide e-mail and telephone support to new and existing members
- Assist members with financial support for attending conferences

Significant activities

Vasculitis Ireland Awareness provides a range of support services to individuals living with Vasculitis Diseases. These services include information, befriending, group meetings, e-mail and telephone support. Vasculitis Ireland Awareness also supports research into the causes and treatment of Vasculitis diseases.

To support these services financially, Vasculitis Ireland Awareness receives donations from the general public in both Northern Ireland and the Republic of Ireland. Vasculitis Ireland Awareness also carries out a range of fundraising activities including quizzes, coffee mornings and a range of one-off events throughout each year.

Beneficiaries

Vasculitis Ireland Awareness is an island of Ireland support group set up in 2010 and services are available to anyone affected by any of the Vasculitis diseases in Ireland. It is recognised as a charity in both Northern Ireland and the Republic of Ireland.

OBJECTIVES AND ACTIVITIES

Public benefit

The trustees are confident that the charitable aims of Vasculitis Ireland Awareness satisfy the principles of public benefit as defined in the Charities Act. They have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the aims and objectives and in planning its future activities.

How the charity activities deliver public benefit

The charitable activities focus on supporting the needs of people with any of the Vasculitis diseases and are undertaken to further the charitable purposes for the public benefit.

The principal aim of the charity is that of providing information, advice and guidance to people affected by any of the Vasculitis diseases, providing support and raising awareness of these diseases, and improving services and care for those affected by Vasculitis diseases. E-mail and telephone support is also facilitated.

The trustees believe equal access to its services is vital to its success, and that successful outcomes must be shared by all communities that use its services.

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ACHIEVEMENT AND PERFORMANCE

Charitable activities

Vasculitis Ireland Awareness continues to focus on producing outcomes which bring real and tangible benefits to people living with Vasculitis diseases. At all times, Vasculitis Ireland Awareness maintains its constant commitment to developing the range and quality of support offered to individuals living with Vasculitis diseases throughout Ireland.

The drive and determination of Vasculitis Ireland Awareness to maintain its level of service delivery and look at the development of new services can only happen with the continuing support of the Vasculitis Ireland Awareness Committee and its members.

The charity delivers its services directly to people to provide information, friendship and support as well as to reduce the isolation felt by many of those living with Vasculitis diseases.

Vasculitis Ireland Awareness continues to contact consultants to inform them of their existence and to provide them with information on upcoming events, in the hope that they will share these with the attendees of their clinics. This is an effective way of raising awareness of our services and reaching out to those in need of assistance, as well as receiving referrals from these practitioners.

The continuing presence of COVID in society meant that most of our business had to continue being held online. Our community remained vulnerable with uncertainties about how COVID 19 would affect us and the effectiveness of the new vaccinations. This brought further anxiety and worry, and it was important to ensure we were available to provide current advice and information to help alleviate these. With this in mind, we established several main priorities to help us meet this requirement.

Our priorities this year were to

- have online meetings on current issues, available services, self-management and opportunity to just talk – for all living with vasculitis including their carers.
- improve our online presence considering our reliance on it throughout the pandemic. – investigate improving our website, mailing list, creating a closed group forum and operating social media
- Deliver a hybrid International Vasculitis Patient event in conjunction with the International ANCA and Vasculitis Symposium held in Dublin.
- Investigate the feasibility of setting up a ‘Buddy Scheme’ for Peer Support, whereby members can support newly diagnosed people.
- look into possibility of recruiting more volunteers to help with managing the charity support group

We spent a lot of the beginning of the year focusing on preparing to host and deliver the International Vasculitis Patient event in conjunction with The International Vasculitis and ANCA workshop held in Dublin in April 2022. We wanted to avail of the opportunity to have world renowned international speakers at our event and share this with our worldwide patient community.

We continue our close working relationship with other patient groups, mainly but not only, Vasculitis UK, Vasculitis International, Northern Ireland Rare Disease partnership, Rare Disease Ireland, and Irish Platform for Patient Organisations, Science and Industry. This year has seen us work closely with Vasculitis Foundation and Vasculitis Stichting in delivering the Patient event. This has helped us shape future care and provide input at policy level in all the jurisdictions. For example, we were successful in ensuring our community had earlier access to the COVID Vaccine than the original policies had outlined. We have also been fortunate to be invited to participate in European wide projects so our local voice can be included. We continue to link with local organisations to help our members access resources to help with the management of their conditions, i.e. Arthritis Ireland, Northern Ireland Rare Disease Partnership, Volunteer Ireland.

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Julie remained as Chair to oversee the international event and allow time to train up the next Chair. Cecil has continued as secretary and we welcomed two new board members Sarah Flynn, (NI) who brings a background in psychology and Tadhg Treacy (RoI) who brings a background of governance. Jennifer Kelly has accepted the role of Volunteer Co Ordinator, Vivienne Beattie continues to be our Mediator, Tim Whymark is now our RoI treasurer.

We also were fortunate to recruit several volunteers to help us with specific roles.

- Seamus Beausang who has been instrumental in creating new contact cards, and brochures and getting these to all clinics so newly diagnosed patients know of us.
- Margaret Dunne, Immunologist and TCD lecturer who has helped us improve our Patient and Public Involvement presence in research projects.
- Maria Christofideau – Early-stage researcher within several research projects we are involved with, who has a legal background and helps us with GDPR, privacy and data protection issues.

Providing Support

All meetings were held online due to the ongoing Covid situation and a steady flow of new contacts were added throughout the year via the Facebook page and the helpline number.

This year our secretary spent some time designing a form to enrol in our membership, outlining the different levels of participation one can opt into. This will make this process much easier for all concerned going forward.

Support continues to be provided by email and telephone - providing reassurance and guidance when needed. Continued contact with the consultants in the Vasculitis Ireland Network – VINE – ensures the correct procedures are adopted when seeking an initial referral.

The awareness campaign led by Seamus, helped us reach more rural healthcare clinics and resulted in queries from healthcare professionals re our work and how we can work together.

Summary of meetings in 2022

Due to the organisation involved in the International event, there were fewer meetings planned this year. Our membership have access to all recordings in the Vasculitis International website and can view them in their own time. This content is quite detailed and delivered by world renown physicians. The fact that some of our board members contracted COVID also meant that there were few meetings from June on.

January 18th 19.00 – 20.15 Online

Online Debunked workshop - workshop to help people identify misleading or misrepresented information and provide some simple techniques to separate fact from fiction. This is very important in the current times with so many versions of facts circulating.

Delivered by ADAPT team TCD

March 14th 19.00- 20.15

Online Coffee and Chat

Informal online meeting for members to meet and talk about current issues, share experiences and support each other.

Programme

April 2nd and 3rd from 12.00 noon on 2nd to 1pm on 3rd

International Vasculitis Patient event – Hybrid and translation available in 22 languages

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Agenda

Saturday April 2nd, 2022

Time	Topic	Speaker(s)
13.05-13.20	Introduction Patient experience - Living with Large vessel Vasculitis	
13.25-14.00	Vasculitis Today a Worldwide Round Table Discussion (Chair: Peter Verhoeven and Joyce Kullman)	Prof. David Jayne (UK) Prof. Richard Kitching (Australia) Prof. Peter Merkel (USA) Prof. Kevin Cassar (Malta)
14.05-14.35	Covid 19 and Vasculitis, Effectiveness of vaccinations and boosters (Chair: Dr. Michael Clarkson)	Dr. Stephen McAdoo Dr. Emma Leacy Dr. Matthias Busch
14.40-14.55	Managing Fatigue in vasculitis	Prof. Lorraine Harper
15.00-15.30	Break – tea/ coffee	
Room 1		
15.30 – 15.50	Cardiovascular risk in ANCA vasculitis	Dr. Eline Houben
15.55 – 16.15	Environmental triggers in vasculitis	Albert Navarro Gallinad Enock Havyarimana
16.20 – 16.40	Giant cell arteritis (Chair: Dr. Eamonn Molloy)	Farah Kamberović Michal Žulciński
16.45 – 17.00	Wrap up Day 1 – Room 1	Joyce Kullman & Zdenka Hrušková
Room 2		
15.30-15.45	Vasculitis in children	Dr. Louise Oni
15.50-16.05	Microbiomes and vasculitis	Dr. Andreas Kronbichler
16.10-16.25	Molecular Influences in vasculitis	Solange Gonzalez Chiappe Gisela Pattarone
16.30-16.45	Data protection in vasculitis research	Maria Christofidou
16.45-17.00	Wrap up Day 1 – Room 2	Peter Verhoeven
19.30-22.00	Dinner – optional	

Sunday 3rd April, 2022

09.30-09.35	Introduction to Day 2	Julie Power
09.35-11.00	<i>Patient Reported Outcomes</i>	Chair: Zdenka Hrušková
09.35-09.45	PROs and PROMs in perspective	Prof. Peter Merkel
09.45-09.55	The FAIRVASC project	Dr. Matthew Rutherford
09.55-10.05	Why PROs in Registries	Peter Verhoeven
10.05-10.15	How to integrate PROs into Registries	Nathan Lea
10.20-10.40	Discussion: Most useful PROs: the patient perspective	All
10.45-11.00	Break – tea/ coffee	
11.10-11.35	<i>What good care looks like</i>	
11.00-11.20	The VOICES project	Dr. Allyson Egan Dr. Rosemary Hollick
11.20-11.35	ERN RITA Patient journeys	Julie Power
11.40-12.45	Multidisciplinary Art Workshop: Art, Vasculitis and the Lived Experience – Capturing the Invisible	Dr. Shanali Perera
12.45-13.00	Wrap up and closing remarks	Julie Power

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This was a successful event with people joining from all over the world with up to 80 participants on site and between 40-100 online at any one time.

May 23rd – 19.00- 20.15

Induction training for board members and volunteers – online

9th August 19.00-20.15

Coffee and Chat – Informal discussion between members, catching up, sharing news

27th October 19.00 – 20.15

Coffee and Chat – Informal discussion between members, catching up and sharing news.

28th November 19.00- 20.15 online

Let's Talk About Avacopan – discussion on experiences with/without Avacopan in preparation for NCPE submission for Avacopan approval.

We continue to work on setting up a 'Buddy scheme'. Several members have expressed an interest and we are ensuring all safeguarding is in place before this becomes operational. This will become an option to opt in to when we have a fully operational membership button on our website.

Raise Awareness

As stated earlier, Seamus has been instrumental in increasing our profile in nephrology and rheumatology clinics throughout Ireland/Northern Ireland. We have designed a new flyer and contact cards and these have been distributed to the clinics in the hope that staff and patients become aware of our support group.

We have been involved in several education initiatives during the year, giving input and presentations to healthcare professionals, nursing students, medical graduates, rare disease community and researchers, about the experience of living with vasculitis.

January – Public and Patient Involvement (PPI) conversation with UCD Children's nursing students, online talk about living with rare disease and effects on family.

February

1st February online meeting with Roscommon Volunteer centre online to raise awareness of VIA and what we do.

28th February International Federation of Nursing Associations UK and Ireland Webinar
'Reshape, Reform, Reimagine a true partnership with families living with rare disease'
Presentation on effects of living with rare disease on family.

March

24th March Presentation to UU Physiotherapy students online
'Impact of professions allied to medicine input in managing vasculitis'

April

Interview with Rare Revolution magazine on the International Vasculitis Patient event and registries.

May

25th May NIRDP filming
Living with Vasculitis – diagnostic odyssey through to management

June

8th June Rare Diseases Forum online organised by HCRI
Shared talk with Prof Suja Somanadhan on PPI and Collaboration

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October

26th October online Portugal Erasmus training
Presentation on Privacy concerns when dealing with patient data.

November

2nd/3rd Face to face meeting in Madrid Vasculitis International and Vifor Pharma
Design of information materials for those living with AAV

We have had active involvement in several groups/projects ensuring the patient voice is incorporated into projects

- January - February – part of organising committee for events on Rare Disease Day being organised by RDI and NIRDIP
- IPPOSI Policy Committee – active input to healthcare policies in HSE - ongoing
- IPPOSI Education and Training Advisory Group – input to and developing Patient education programme (research and development, engagement in policy making) - ongoing.
- HRB Clinical Research Consortium Ireland (CRCI), Patient and Public Involvement working group, to help educate the importance of patient involvement throughout the whole process of policy making, developing services and research – ongoing
- ENP Ireland (European National Platform) – this is a conglomeration of patient advocates from different backgrounds who have been involved in either the EUPATI programme or the Irish Patient Education programme, academics and researchers interested in Patient and Public involvement. This is a space to share experiences and learn from each other.

This year we marked International Vasculitis Day on May 15th with picnics in Co. Down and Co. Dublin.

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Improve services and care for those affected by Vasculitis, and support Vasculitis research

The charity continues to be an all-island of Ireland charity, registered both in ROI as well as Northern Ireland. The belief is that registration as a cross -border charity in Ireland will improve services for patients, giving them access to both jurisdictions as well as an avenue to European and International activities. This continues to be a challenge as the UK leaves the European Union.

Through work carried out with RDI, IPPOSI and NIRDP, the issue of access to treatments and vaccines during the pandemic was able to be addressed. Working with these organisations, ensured the Vasculitis voice was included in any considerations at national level.

ROI.

Membership of EURORDIS ensures the charity is kept aware of any developments and training opportunities at European level. VIA is now a member of the rare disease GO FAIR patient network <https://www.go-fair.org/>, which involves participating in monthly meetings, to look at what is involved in setting up patient registries, and electronic healthcare records and how to make best use of these.

The charity is also involved in the ERN RITA European Patient Advocacy Group (ePAG); this has helped to promote the charity's work at a European level and also allowed members to benefit from learning from European colleagues. Julie sits on the RIPAG board and is the Auto Immune Patient Stream lead on the RITA Board. This involves monthly online meetings to discuss how to incorporate the patients voice into access to care in a meaningful way that will improve patients' lives throughout Europe. This year the Patient Journey project was started, initially concentrating on the Small Vessel Vasculitis Journey. The plan is to eventually have similar for all classifications of vasculitis so that a uniform approach can be considered when devising care pathways and clinical guidelines.

Research

Ongoing collaborations with UKIVAS has continued and this has been very useful in obtaining appropriate information on COVID-19 as well as vaccinations, to pass on to the members .

The charity continues to have input to the Steering Committee of the Rare Kidney Disease Registry (RKD) to oversee and approve actions within this group, ensuring the patient perspective is considered at every stage.

Regular fortnightly virtual meetings with the AVERT project research team are attended and this provides links between patient group and researchers. This year the charity worked with Mark Little's team on an ethically-approved research project looking at experience of vasculitis flares in the last three years. This looks at what can be recognised as a flare and how to get diagnosed. This information will help determine if the time to diagnosis or starting treatment can begin sooner.

Another aspect of the AVERT project is looking at how to improve the quality of information being gathered by the PatientMpower app. This involved work between the researchers, the study nurse, the technicians and patients and will lead to more reliable accessible information for the study. The appointment of a new research nurse has created a link between the participants and the project and a monthly update for our members became available for the first time.

The charity is involved in the newly-established research project DeComPRESS, which looks at COVID-19 and Vasculitis – the susceptibility to COVID, how immune systems react to both COVID and the vaccinations, and what are the long-term implications if COVID-19 is contracted. This involves monthly online meetings.

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The HELICAL research project was launched in Trinity College Dublin, in December 2019. This is a European project and involves 32 early-stage researchers investigating various biological and environmental factors which affect Vasculitis. Julie and a patient representative from the Netherlands Vasculitis group have been invited to participate in this project to ensure patient perspective is evident throughout. Work has started in ensuring all research consent documents are transparent and the information they contain is readily understood by patients. There have also been discussions about what patient data means to patients and their concerns in using this in research. This involves up to six meetings a year.

Here are further links to information on the ongoing research projects:

<http://helical-itn.eu/research-projects/>

<http://helical-itn.eu/research-projects/esr15/>

FAIRVASC <https://fairvasc.eu/> is a Europe wide project looking at the interoperability of existing vasculitis registries and how to combine these to create a large data base which can facilitate meaningful research. VIA is one of the three patient organisations involved in this. Julie attended the EJP RD week-long course on Rare Disease Registries and FAIRification of Data in September and this has proved very useful in understanding the work in FAIRVASC. As part of this project €50,000 was invested in Vasculitis International over the three-year period of this project. This involves several half day meetings a year.

PARADISE This is a new project with our European colleagues which has been recently approved. The concept of this will be to develop a means of personalised medication to reduce the side effects when treating AAV.

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ACHIEVEMENT AND PERFORMANCE

Charitable activities

An annual conference is held each year for members and their family members to attend. The annual conference is very informative, giving information on the latest research and development. It is presented by guest speakers. Members can make suggestions for which topics they would like covered and a particular speaker in that field is sought. Members find the annual conference very worthwhile.

FINANCIAL REVIEW

Financial position

The financial position of the charity can be found on pages 12 and 13.

Principal funding sources

The principal funding sources for the charity are currently from donations and fundraising activities.

Reserves policy

Due to the unpredictability of the income receivable by the charity it is the policy of Vasculitis Ireland Awareness to maintain a balance on unrestricted funds to cover emergency situations that arise from time to time and to also enable the charity to continue to deliver its service effectively.

The present level of reserves available to the charity is £19,303.

FUTURE PLANS

The charity plans continuing the activities outlined above in the forthcoming years subject to satisfying funding arrangements.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document and constitutes an unincorporated charity.

Recruitment and appointment of new trustees

A broad mix of skills are represented on the Management Committee and all Trustees are chosen on the basis of their willingness to serve, ability, governance experience and support of the ethos, mission and philosophy of the organisation.

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

N Ireland: 105731

Ireland: 20204769

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FOR THE YEAR ENDED 31 DECEMBER 2022**

REFERENCE AND ADMINISTRATIVE DETAILS

Principal addresses

45 Castle Street
Killough
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BT30 7QQ

The Gate Lodge
Park House
Bawn Street
Strokestown
Roscommon
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F42 P285

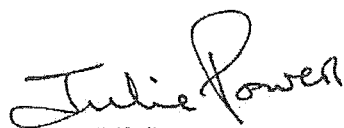
Trustees

Julie Power
Cecil Armstrong
Jennifer Kelly
Sarah Flynn
Vivienne Beattie
Timothy Whymark
Tadhg Treacy

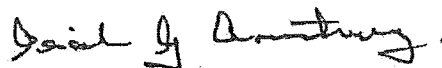
Independent examiner

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Approved by order of the board of trustees on 30/10/2023 and signed on its behalf by:



**Julie Power
Trustee**



**Cecil Armstrong
Trustee**