

**REGISTERED CHARITY NUMBER**

**N Ireland: 105731**

**Ireland: 20204769**

**REPORT OF THE TRUSTEES AND  
RECEIPTS AND PAYMENTS ACCOUNTS  
FOR THE YEAR ENDED 31 DECEMBER 2023  
FOR  
VASCULITIS IRELAND AWARENESS**

VASCULITIS IRELAND AWARENESS

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FOR THE YEAR ENDED 31 DECEMBER 2023

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## VASCULITIS IRELAND AWARENESS

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2023

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The trustees present their report with the financial statements of the charity for the year ended 31 December 2023.

#### 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 was 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. – employing a website designer, improve process to join our mailing list, and operating social media. The work on our website became increasingly urgent as our old one has become very difficult to update.
- Explore resources needed and needs of our patient community in 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.
- Developing networks with researchers, clinicians and Organisations to help with improving vasculitis care and management in Ireland.

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. 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.

We have also been actively involved within RITA Ireland and ERN RITA in working with our EU colleagues in the world of rare disease and Vasculitis.

In April, we began discussions with Urban Brand Creative to help us design a new and more accessible website. Throughout the year, we spent a lot of time collecting the information our members needed and requested and relaying this to UBC.

##### Roles

Julie remained as Chair and will hand over to Cecil at the AGM in January. Cecil has continued as secretary, and we are actively seeking a replacement. Tadhg Treacy (RoI) has taken over the role of Governance Officer and has overseen updating all our Policies and Procedures in accordance with both the Charity Commission of NI and the Charities Regulator in ROI. Jennifer Kelly has accepted the role of Volunteer Co Ordinator, Vivienne Beattie continues to be our Mediator, Tim Whymark is our RoI treasurer.

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We also were fortunate to retain 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**

We held all our meetings online due to the ongoing COVID situation and reduced manpower and finances to set up face to face meetings. We have had a steady flow of new contacts throughout the year via our Facebook page and helpline number. This year we spent time updating a form to enrol in our membership, outlining the different levels of participation one can opt into. We also set up a Mailchimp system to send out our emails on a regular basis so that people can be fully informed of any Vasculitis news.

We continue to provide support by email and telephone - providing reassurance and guidance when needed. We liaise closely with the consultants in the Vasculitis Ireland Network (VINE) to ensure 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. We have also worked with some clinicians to ensure that brochures and our support group contact cards are available at clinics.

We continued work on the “Buddy Scheme which changed names several times to reflect the service we could provide. We spent a long time exploring what was actually needed by our members and the resources available to us. This time is important to ensure we manage expectations and provide a service which is fit for purpose.

#### Summary of Support Group meetings in 2023

January 9th 19.00 – 20.15 Online

Talk from RNID about hearing loss and how to manage it. Hearing loss is very common amongst our members and this talk and discussion delivered by RNID was very useful, to explain the resources they have available to deal with this issue. A recording of the talk is on our You Tube members channel at [https://youtu.be/LzpjSObmwF8?si=iLbo4\\_8FoXIUSW9f](https://youtu.be/LzpjSObmwF8?si=iLbo4_8FoXIUSW9f)

February 6th 19.00- 20.15

Online Talk from Prof David Jayne from Addenbrookes, Vasculitis clinic Cambridge about all things Vasculitis. This was a well-attended meeting to hear from one of the top vasculitis consultants in the world. A recording of his talk is on our YouTube members channel at <https://youtu.be/JjHBluPLWyY?si=fUEeI7EReBxB8UjU>

6th March 19.00-20.15

Online Coffee and Chat - informal discussion between members, catching up and sharing experiences in managing Vasculitis.

3rd April 19.00-20.15

Online, Dr Sinead Stoneman (Cork University Hospital) presenting a new renal app she is proposing to develop and looking for feedback from the patient community on content and feasibility.

9th May, 19.00-20.15

Online Results of AVERT study - effects of UV/Vitamin D on Vasculitis by Dr Jennifer Scott, Tallaght Hospital

5th June 19.00-20.15

Online Coffee and Chat

From 25th September we ran a series of weekly presentations from the EULAR symposium with opportunity for discussion afterwards

25th September 19.00-20.15

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Online Rare Muscular Disorders(RMDs) and Co morbidities

1. RMDs, Cancer and Mental Health – how are they connected?
2. RMDs and possible comorbidities – a patient perspective
3. RMDs and co morbidities, can psychology help?

2nd October 19.00-20.15

Online RMDs and Comorbidities continued.

1. Creativity and co production to support people living with chronic pain and their mental health.
2. Preliminary findings of Qualitative Exploration of the effectiveness of an online Fatigue and Activity Management education in work (FAME\_W) intervention for people with inflammatory arthritis.

9th October 19.00- 20.15

Online Living and planning life while co-existing with an RMD

To offer solutions to challenges faced by patients in planning their lives.

To inspire patients to live life to its fullest

1. Love, live, work and PsA - my story
2. Understanding the impact of RMD on work life
3. Mindfulness - Balancing life with a chronic illness

16th October, 19.00-20.15

Online Living and planning life while co-existing with an RMD with emphasis on having a family

1. Same-Same or different - RMDs and planning a family
2. What are the unmet needs of pregnant patients diagnosed with inflammatory rheumatic diseases receiving care in a highly specialised reproductive rheumatology centre? The results of the CAPRI study.

23rd October

No meeting

30th October, 19.00-20.15

Online Large Vessel Vasculitis

An update on the use of various diagnostic modalities and treatment options, including biological agents, in large vessel vasculitis (Takayasu, aortitis, GCA)

Talk on Large Vessel Vasculitis

6th November 19.00-20.15

Online ANCA Associated Vasculitis

Review and discuss the current advances in ANCA associated vasculitis.

Present the new EULAR/ACR classification criteria with discussion of new insights into vasculitis subtypes.

Discuss EULAR and other management recommendations for ANCA-associated vasculitis.

Discuss new and emerging therapies for ANCA vasculitis such as complement inhibition.

1. Recommendations for management of ANCA associated vasculitis
2. Insights from new 2022 EULAR/ACR classification criteria

13th November 19.00-20.15

Online ANCA Associated Vasculitis (ctd)

1. Newer treatments for ANCA Vasculitis - David Jayne
2. Benralizumab for EGPA: results from a European multicentre study on 121 patients
3. The burden of multi morbidity in ANCA associated Vasculitis: A cohort study

20th November 19.00-20.15

Data Matters

To highlight the role of patient organisations in data collection for registries and records.

To learn what is important for patients and organisations in relation to data collection and clinical trials.

1. Facilitate data sharing, re-use and return of clinical trial data to study participants
2. Patients' involvement in registries and biobanks: The Rare Kidney Disease Registry and Biobank (Julie)

27th November 19.00-20.15

Online. Exercise beyond Drugs - Importance of being physically active

To explain the evidence for physical activity as an integral part of standard care for people with RMDs.

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To implement the use of exercise in the care of people with RMDs; and explain benefits of exercise in prevention and rehabilitation, with examples such as strength, endurance, and joint mobility improvements.

1. What can we do to support our patients to become more physically active?
2. The importance of aerobic capacity for the risk for cardiovascular diseases in patients with inflammatory arthritis

4th December 19.00-20.15

Online. Exercise beyond Drugs - Importance of being physically active (ctd)  
Strength maintenance and development as a pillar of health.

#### **Raise Awareness**

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 28th – Winter Irish Nephrology Society meeting – Julie was invited to speak about Research from the Patient's Perspective. Feedback from this was relayed back via one of our members who was told by their consultant that he now took patient perspective into consideration with his consultations.

6th-9th February – Invited participation in EURORDIS Rare Disease week, advocating for Europe wide Rare Disease Action Plan, more recognition of Mental Health issues in Rare Disease, and for a patient driven evolution of the Orphan Medicinal Product Regulation - addressing unmet needs. This involved meetings with three Irish MEPs to discuss these issues with regard to Ireland.

28th February International Rare Disease Day in Stormont where we had an information stand and had the launch of 1 in 17 Rare Voices series developed by NIRDP featuring Julie. This video is also on our YouTube members channel at <https://youtu.be/GSsVSIY6nLM?si=YsvxGfBMHUEwoYT3>

4th May – All Ireland Interdisciplinary Rare Disease Network webinar. Description: All Ireland Rare Disease Interdisciplinary Research Network ( RAIiN) is a collaborative effort between rare disease interdisciplinary researchers and community groups across Ireland. This research was funded by the Shared Island strand of the Irish Research Council's New Foundations programme. This network focus is:

- i. To bring together interdisciplinary researchers, practitioners, and policymakers in the Island of Ireland to form an interdisciplinary research network to improve awareness of and participation in rare diseases research.
- ii. To address an area of unmet need of children and young people living with rare diseases and their families with a comprehensive interdisciplinary and intersectoral approach that places patients and their needs at the centre. Building on established research partnerships RAINDROP(ROI) and RARDTAC(NI) while developing new interdisciplinary rare disease research networks to inspire and empower early career researchers as emerging leaders.
- iii. Researchers exploring issues affecting people living with rare health conditions across the lifespan presented their work at the webinar.

19th May, Services for People with Systemic Vasculitis – online webinar discussion with others involved in the VOICES project. Giving Irish perspective.

31st May-3rd June – Julie was an invited speaker at EULAR conference in Milan, to speak about patient involvement in Registries and Biobanks.

8th June Introduction call with Devra Densmore, Global Patient Advocacy Argenx - a biotech focused on potential immunological treatments, who are interested in learning more about what is most important to people living with ANCA Vasculitis.

12th June, Introduction call with Syneos to connect about how we may be able to collaborate to raise awareness of an EGPA clinical study for patients and healthcare professionals.

15th-17th June ERN RITA annual General Meeting – raising awareness of complications involved in Patient Journey and how do we address these together.

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27th June 2nd RAiN webinar

30th November-2nd December Participation in i-HD annual meeting in Ghent to present about the importance of transparency in research when working with patient data.

#### **Improve services and care of those living with Vasculitis and support Vasculitis Research**

We are a registered charity in RoI as well as Northern Ireland and operate as an all island of Ireland charity. We believe that registration as a cross -border charity in Ireland will improve services for patients, as this will give access to both jurisdictions an avenue to European and International activities. This continues to be a challenge for us to face as the UK leaves the European Union.

Through our work with RDI, IPPOSI and NIRDP, we were able to address the issues of access to treatments and vaccines during the pandemic. We ensured the Vasculitis voice was included in any considerations at national level through working with these organisations.

As members of EURORDIS we are 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.

We are involved in the ERN RITA European Patient Advocacy Group (ePAG); this has helped to promote our work at a European level and allowed us to benefit from learning from our 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 have the patient voice incorporated into access to care in a meaningful way that will improve patients' lives throughout Europe. This year we completed work with the Patient Journey project concentrating on the Small Vessel Vasculitis Journey. This has been reviewed by European clinicians specialising in SVV and has been well received. It is now being advised as an information resource for people living with SVV, those involved in their care and those planning services by the clinicians in UKIVAS.

Cecil has been actively involved with encompass – the new Digital Care Record system for very citizen in NI. He is a member of the encompass Engagement Council and is a patient representative on the Information Governance Advisory Council and the My Care regional Governance and Decision Group.

#### **Research**

We have ongoing collaborations with UKIVAS which has been very useful in helping us get appropriate information on COVID and vaccinations to our members quickly.

We 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.

We continue to attend regular monthly virtual meetings with the FAIRVASC. 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. In recognition of our work, up to €50,000 has been invested in Vasculitis International over the three-year period of this project. This is being used to help support other vasculitis groups throughout Europe.

This is the last year of the FAIRVASC project and in January 20-21st, we were in Krakov looking at what we need for onboarding new registries and had a hackathon in the local university to look at ways of improving the interface and future proofing this. We find this is a successful project and are looking at ways of continuing this beyond the existing grant. To this end we (the FAIRVASC team which has strong patient involvement) are looking at ways of making this a sustainable entity which is acceptable to the public.

PARADISE This is a new project with our European colleagues which has been recently approved. <https://paradise-project.eu/>. The concept of this is to use existing data to help develop an algorithm which will predict the probability of flares. By having a tool like this, medication levels can be reduced or even stopped if there is low probability of relapse. The project launched officially in April and Julie is one of the research partners. Patient voice is paramount to this project to determine acceptability of using AI in moderating treatment plans, ensuring that the concept is transparent to both researchers and the public so that the concept is transferable beyond Vasculitis. We have an active Patient

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Advisory Group from all over Europe to help direct the project and also a team of Irish patients who will help review materials further. There was a plenary meeting in Zagreb in October 23rd -24th October.

We were contacted by several companies (Astra Zenica and Syneos on behalf of GSK) wishing our assistance in finding patients with EGPA willing to participate in surveys and focus groups. This information was circulated to the members for their information.

#### Finance

This year the big expenditure was the deposit for developing our new website which was £2,787.09 paid in April.

#### Governance costs

We had annual Accountant and Insurance costs as per Charity governance requirements. Our Insurance has to cover both jurisdictions.

#### Meetings

We rely heavily on the Zoom package to carry out all our online meetings. This incurs a monthly charge to include cloud storage when necessary.

#### Stationery and Electronics

We had no stationery costs this year.

#### Fundraising

Unfortunately, as we were concentrating on improving our website and listening to our membership on what they want, we did little fundraising this year. We did have a birthday Facebook fundraiser which raised £193.36 which was paid into our PayPal account.

Setting up a Facebook Fundraiser is quick and easy. The fundraiser could be for your birthday instead of receiving gifts; it could be to take on a challenge or perhaps to remember a loved one on a special anniversary; it could be donations in lieu of wedding favours or Christmas cards. Facebook charges no fees on donations made so every penny your friends and family donate through a Facebook fundraiser comes directly to VIA. Simple instruction on how to do this are on our website at <https://www.vasculitis-ia.org/get-involved>

## ASCULITIS IRELAND AWARENESS

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2023

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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 11 and 12.

##### 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 £14,654.

#### 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 2023

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REFERENCE AND ADMINISTRATIVE DETAILS

Principal addresses

45 Castle Street  
Killough  
Co. Down  
BT30 7QQ

The Gate Lodge  
Park House  
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F42 P285

Trustees

Julie Power  
Cecil Armstrong  
Vivienne Beattie  
Timothy Whymark  
Jennifer Kelly  
Tadhg Treacy  
Clara Coady

Independent examiner

M.B.McGrady & Co  
Chartered Accountants  
Rathmore House  
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BT30 6DS

Approved by order of the board of trustees on 17.10.24 and signed on its behalf by:



Julie Power  
Trustee

Patient Contact  
Officer



Cecil Armstrong  
Trustee

Chair