Vasculitis Ireland Awareness

Northern Ireland · Charity number 105731

Details

Status	Received
Registered	2016-10-17
Register	View on the Charity Commission for Northern Ireland register

Contact

Address	45 Castle Street Downpatrick Bt30 7qq BT30 7QQ
Phone	028 44 842889
Email	vasculitis10@gmail.com
Website	www.vasculitis-ia.org

Activities

Purposes: The association is established to improve the quality of life of people suffering from Vasculitis and their carers living in Ireland, irrespective of age, sex, disability, race, sexual orientation, political, religious or other opinion, by associating with statutory authorities, voluntary and community organisations and the private sector.

What the charity does: The advancement of health or the saving of lives,The relief of those in need by reason of youth, age, ill-health, disability, financial hardship or other disadvantage

How the charity works: Advice/advocacy/information,Counselling/support,Cross-border/cross-community,Disability,Education/training,Medical/health/sickness,Research/evaluation

Who the charity helps: Carers,Men,Mental health,Older people,Parents,Physical disabilities,Sensory disabilities,Women

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£27,374	£10,196	£0	0

Trustees

Name	Role	Appointed
Mr Cecil Armstrong		
Mr Conor O'brien		
Mr Timothy Whymark		
Mrs Ciara Coady		
Mrs Julie Power		
Ms Victoria Kavanagh		
Ms Vivienne Beattie		

Vasculitis Ireland Awareness

Northern Ireland - Charity number 105731

Accounts

RECEIPTS AND PAYMENTS ACCOUNTS
FOR THE YEAR ENDED 31 DECEMBER 2024

	Notes	2024 Restricted Fund	2024 Unrestricted Fund	2024 Total	2023 Unrestricted Fund
		£	£	£	£
RECEIPTS FROM					
Unrestricted grant			12,240	12,240	-
Restricted grant		5,000	-	5,000	-
Donations and Legacies		-	8,634	8,634	557
Honorarium receipts		-	-	-	844
Investment income	2	-	47	47	58
Other trading activities	2	-	1,453	1,453	343
Total		5,000	22,374	27,374	1,802
PAYMENTS ON					
Raising funds		-	-	-	-
Charitable activities					
Charitable		-	10,196	10,196	6,451
Total		-	10,196	10,196	6,451
EXCESS OF RECEIPTS OVER PAYMENTS		5,000	12,178	17,178	(4,649)
Total funds brought forward		-	14,654	14,654	19,303
TOTAL FUNDS CARRIED FORWARD		5,000	26,832	31,832	14,654

STATEMENT OF ASSETS AND LIABILITIES
AT 31 DECEMBER 2024

	2024 Restricted Fund	2024 Unrestricted Funds	2024 Total	2023 Unrestricted Fund
	£	£	£	£
FIXED ASSETS				
Computer & Printer	-	882	882	882
CASH FUNDS				
Bank current accounts	5,000	25,950	30,950	13,772
TOTAL FUNDS	**5,000**	**26,832**	**31,832**	**14,654**

The financial statements were approved by the Board of Trustees on 22nd October 2025 and were signed on its behalf by:

Cecil Armstrong
Trustee

Julie Power
Trustee

Julie Power.

1. ACCOUNTING POLICIES

Basis of preparing the financial statements
The financial statements of the charity, which is a public benefit entity, have been prepared in accordance with the Charities Act (Northern Ireland) 2008 using the Receipts and Payments basis.

Taxation
The charity is exempt from tax on its charitable activities.

Fund accounting
Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. OTHER TRADING ACTIVITIES

	2024 £	2023 £
Foreign Exchange Gain on Euro bank accounts	-	325
Fundraising	788	-
Other	665	18
Fundraising events	1,453	343

3. INVESTMENT INCOME

	2024 £	2023 £
Deposit account interest	47	58

VASCULITIS IRELAND AWARENESS

DETAILED STATEMENT OF RECEIPTS AND PAYMENTS FOR THE YEAR ENDED 31 DECEMBER 2024

	2024 £	2023 £
RECEIPTS		
Grants received		
Vifor grants received	7,135	-
Trinity College	4,970	-
AIB Community Fund	5,000	-
Evolve	135	
Honorarium Receipts	-	844
Donations and legacies		
Donations	8,634	557
Other trading activities		
Fundraising events	-	-
Other	1,453	18
Foreign Exchange Gain	-	325
	27,327	1,744
Investment income		
Deposit account interest	47	58
Total incoming resources	27,374	1,802
PAYMENTS		
Other trading activities		
Foreign Exchange Loss	256	-
Charitable activities		
Donations	-	-
Honorarium payments	-	844
Conferences/Meetings	5,778	1,455
	6,034	2,299
Support costs		
Management		
Professional Fees	732	708
Postage, Printing and stationery	-	-
Sundries	2,790	2,787
Insurance	582	594
Bank Fees	58	63
	4,162	4,152
Total resources expended	10,196	6,451
Net income/(expenditure)	17,178	(4,649)

Accounts

VASCULITIS IRELAND AWARENESS

RECEIPTS AND PAYMENTS ACCOUNTS
FOR THE YEAR ENDED 31 DECEMBER 2023

	Notes	2023 Unrestricted Fund £	2022 Unrestricted Fund £
RECEIPTS FROM			
Unrestricted grant		-	25,081
Donations and Legacies		557	-
Honorarium receipts		844	-
Investment income	2	58	5
Other trading activities	2	343	5,624
Total		1,802	30,710
PAYMENTS ON			
Raising funds		-	-
Charitable activities			
Charitable		6,451	32,439
Total		(6,451)	(32,439)
EXCESS OF RECEIPTS OVER PAYMENTS		(4,649)	(1,729)
Bank current accounts 1 January		19,303	21,032
BANK CURRENT ACCOUNTS 31 DECEMBER		14,654	19,303

STATEMENT OF ASSETS AND LIABILITIES
AT 31 DECEMBER 2023

	2023 Unrestricted Fund £	2022 Unrestricted Fund £
CASH FUNDS		
Bank current accounts	14,654	19,303
TOTAL FUNDS	14,654	19,303

The financial statements were approved by the Board of Trustees on 17·10·24 and were signed on its behalf by:

Cecil Armstrong
Trustee
Chair

Julie Power
Julie Power
Trustee
Patient Contact Officer

1. ACCOUNTING POLICIES

Basis of preparing the financial statements
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Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. OTHER TRADING ACTIVITIES

	2023 £	2022 £
Foreign Exchange Gain on Euro bank accounts	325	-
Fundraising	-	5,478
Other	18	
Fundraising events	343	5,478

3. INVESTMENT INCOME

	2023 £	2022 £
Deposit account interest	58	5

VASCULITIS IRELAND AWARENESS

DETAILED STATEMENT OF RECEIPTS AND PAYMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

	2023 £	2022 £
RECEIPTS		
Grants received		
Vifor grant received	-	8,392
Pobal Stability Scheme Grant	-	13,689
Honorarium Receipts	844	-
Donations and legacies		
Donations	557	-
Other trading activities		
Fundraising events	-	5,478
Other	18	146
Foreign Exchange Gain	325	-
	1,744	27,705
Investment income		
Deposit account interest	58	5
Total incoming resources	1,802	27,710
PAYMENTS		
Other trading activities		
Foreign Exchange Loss	-	73
Charitable activities		
Donations	-	-
Honorarium payments	844	-
Conferences/Meetings	1,455	26,386
	2,299	26,459
Support costs		
Management		
Professional Fees	708	576
Postage, Printing and stationery	-	524
Sundries	2,787	1,248
Insurance	594	580
Bank Fees	63	52
	4,152	2,980
Total resources expended	6,451	29,439
Net income/(expenditure)	(4,649)	(1,729)

Vasculitis Ireland Awareness

Northern Ireland - Charity number 105731

Annual report

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

CONTENTS OF THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2023

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.

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.

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_8FoXlUSW9f

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 is 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

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.

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 (RAiN) 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.

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 if 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 ast 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

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 EGPAwilling 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

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

VASCULITIS IRELAND AWARENESS

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2023

REFERENCE AND ADMINISTRATIVE DETAILS

Principal addresses
45 Castle Street
Killough
Co. Down
BT30 7QQ

The Gate Lodge
Park House
Bawn Street
Strokestown
Roscommon
Republic of Ireland
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
52 St Patricks Avenue
Downpatrick
Co. Down
BT30 6DS

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

Julie Power

Julie Power
Trustee
Patient Contact Officer.

Cecil Armstrong
Trustee
Chair

Vasculitis Ireland Awareness

Northern Ireland - Charity number 105731

Annual return

VASCULITIS IRELAND AWARENESS

INDEPENDENT EXAMINDER'S REPORT TO THE TRUSTEES

I report on the accounts for the year ended 31 December 2023 as set out on pages eleven to fourteen.

Respective responsibilities of trustees and examiner
As the charity's trustees you are responsible for the preparation of the accounts in accordance with the Charities Act (Northern Ireland) 2008.

It is my responsibility to:

- examine the accounts under Section 65 of the Charities Act
- follow the procedures laid down in the General Directions given by the Charity Commission (under Section 65(9)(b) of the Charities Act); and
- state whether particular matters have come to my attention.

Basis of the independent examiner's report
I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in in accordance with the General Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act.

My examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters.

My role is to state whether any material matters came to my attention giving me cause to believe:

1. The accounting records were not kept in accordance with section 63 of the Charities Act
2. That the accounts do not accord with those accounting records
3. That the accounts do not comply with the accounting requirement of the Charities Act
4. That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement
I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.

Mr Malachy B McGrady
Chartered Accountants Ireland
M.B.McGrady & Co
Chartered Accountants
Rathmore House
52 St Patricks Avenue
Downpatrick
Co. Down
BT30 6DS

18th October 2024

Vasculitis Ireland Awareness

Northern Ireland - Charity number 105731

Accounts

REGISTERED CHARITY NUMBER
N Ireland: 105731
Ireland: 20204769

REPORT OF THE TRUSTEES AND RECEIPTS AND PAYMENTS ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2022
FOR
VASCULITIS IRELAND AWARENESS

VASCULITIS IRELAND AWARENESS

CONTENTS OF THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

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.

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.

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

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 Michał Żulciński
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	*Patient Reported Outcomes*	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	*What good care looks like*	
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

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

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 NIRDP
- 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.

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.

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.

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

VASCULITIS IRELAND AWARENESS

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2022

REFERENCE AND ADMINISTRATIVE DETAILS

Principal addresses
45 Castle Street
Killough
Co. Down
BT30 7QQ

The Gate Lodge
Park House
Bawn Street
Strokestown
Roscommon
Republic of Ireland
F42 P285

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

Independent examiner
M.B.McGrady & Co
Chartered Accountants
Rathmore House
52 St Patricks Avenue
Downpatrick
Co. Down
BT30 6DS

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

Julie Power

Julie Power
Trustee

Cecil Armstrong
Trustee

VASCULITIS IRELAND AWARENESS

INDEPENDENT EXAMINDER'S REPORT TO THE TRUSTEES

I report on the accounts for the year ended 31 December 2022 as set out on pages twelve to fifteen.

Respective responsibilities of trustees and examiner

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the Charities Act (Northern Ireland) 2008.

It is my responsibility to:

- examine the accounts under Section 65 of the Charities Act
- follow the procedures laid down in the General Directions given by the Charity Commission (under Section 65(9)(b) of the Charities Act); and
- state whether particular matters have come to my attention.

Basis of the independent examiner's report

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in in accordance with the General Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act.

My examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters.

My role is to state whether any material matters came to my attention giving me cause to believe:

1. The accounting records were not kept in accordance with section 63 of the Charities Act
2. That the accounts do not accord with those accounting records
3. That the accounts do not comply with the accounting requirement of the Charities Act
4. That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.

Mr Malachy B McGrady
Chartered Accountants Ireland
M.B.McGrady & Co
Chartered Accountants
Rathmore House
52 St Patricks Avenue
Downpatrick
Co. Down
BT30 6DS

31st October 2023

RECEIPTS AND PAYMENTS ACCOUNTS
FOR THE YEAR ENDED 31 DECEMBER 2022

	Notes	2022 Unrestricted Fund £	2021 Unrestricted Fund £
RECEIPTS FROM			
Unrestricted grant		25,081	1,082
Donations and Legacies		-	6,436
Investment income	2	5	5
Other trading activities	2	5,624	1,481
Total		30,710	9,004
PAYMENTS ON			
Raising funds		-	-
Charitable activities			
Charitable		32,439	2,386
Total		(32,439)	(2,386)
EXCESS OF RECEIPTS OVER PAYMENTS		(1,729)	6,618
Bank current accounts 1 January		21,032	14,414
BANK CURRENT ACCOUNTS 31 DECEMBER		19,303	21,032

The notes form part of these financial statements

VASCULITIS IRELAND AWARENESS

STATEMENT OF ASSETS AND LIABILITIES
AT 31 DECEMBER 2022

	2022 Unrestricted Fund £	2021 Unrestricted Fund £
CASH FUNDS		
Bank current accounts	19,303	21,032
TOTAL FUNDS	17,590	21,032

The financial statements were approved by the Board of Trustees on 26/10/2022 and were signed on its behalf by:

Cecil Armstrong
Trustee

Julie Power
Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements
The financial statements of the charity, which is a public benefit entity, have been prepared in accordance with the Charities Act (Northern Ireland) 2008 using the Receipts and Payments basis.

Taxation
The charity is exempt from tax on its charitable activities.

Fund accounting
Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. OTHER TRADING ACTIVITIES

	2022 **£**	**2021** **£**
Foreign Exchange Gain on Euro bank account	-	-
Fundraising	5,478	671
Fundraising events	5,478	671

3. INVESTMENT INCOME

	2022 **£**	**2021** **£**
Deposit account interest	5	5

VASCULITIS IRELAND AWARENESS

DETAILED STATEMENT OF RECEIPTS AND PAYMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

	2022 £	2021 £
RECEIPTS		
Grants received		
Vifor grant received	8,392	-
Pobal Stability Scheme Grant	-	1,082
EJP RD Grant	13,689	-
Donations and legacies		
Donations	-	6,436
Other trading activities		
Fundraising events	5,478	671
Other	146	810
Foreign Exchange Gain	-	-
	27,705	8,999
Investment income		
Deposit account interest	5	5
Total incoming resources	27,710	9,004
PAYMENTS		
Other trading activities		
Foreign Exchange Loss	73	220
Charitable activities		
Donations	-	140
Conferences/Meetings	26,386	810
	26,459	950
Support costs		
Management		
Professional Fees	576	360
Postage, Printing and stationery	524	-
Sundries	1,248	532
Insurance	580	285
Bank Fees	52	39
	2,980	1,216
Total resources expended	29,439	2,386
Net income/(expenditure)	(1,729)	6,618

Vasculitis Ireland Awareness

Northern Ireland - Charity number 105731

Annual report

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.

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.

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

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 Michał Żułciński
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	*Patient Reported Outcomes*	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	*What good care looks like*	
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

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

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 NIRDP
- 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.

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.

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.

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

REFERENCE AND ADMINISTRATIVE DETAILS

Principal addresses
45 Castle Street
Killough
Co. Down
BT30 7QQ

The Gate Lodge
Park House
Bawn Street
Strokestown
Roscommon
Republic of Ireland
F42 P285

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

Independent examiner
M.B.McGrady & Co
Chartered Accountants
Rathmore House
52 St Patricks Avenue
Downpatrick
Co. Down
BT30 6DS

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

Julie Power

Julie Power
Trustee

Cecil Armstrong
Trustee

Vasculitis Ireland Awareness

Northern Ireland - Charity number 105731

Annual return

VASCULITIS IRELAND AWARENESS

INDEPENDENT EXAMINDER'S REPORT TO THE TRUSTEES

I report on the accounts for the year ended 31 December 2022 as set out on pages twelve to fifteen.

Respective responsibilities of trustees and examiner

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the Charities Act (Northern Ireland) 2008.

It is my responsibility to:

- examine the accounts under Section 65 of the Charities Act
- follow the procedures laid down in the General Directions given by the Charity Commission (under Section 65(9)(b) of the Charities Act); and
- state whether particular matters have come to my attention.

Basis of the independent examiner's report

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in in accordance with the General Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act.

My examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters.

My role is to state whether any material matters came to my attention giving me cause to believe:

1. The accounting records were not kept in accordance with section 63 of the Charities Act
2. That the accounts do not accord with those accounting records
3. That the accounts do not comply with the accounting requirement of the Charities Act
4. That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.

Mr Malachy B McGrady
Chartered Accountants Ireland
M.B.McGrady & Co
Chartered Accountants
Rathmore House
52 St Patricks Avenue
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Co. Down
BT30 6DS

31st October 2023