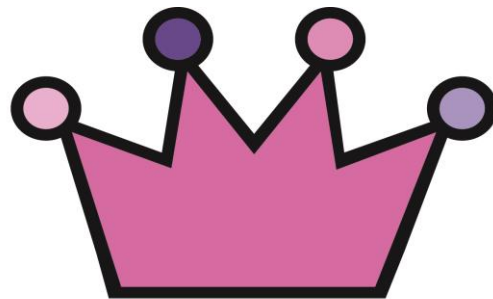




**The Queen's Award  
for Voluntary Service**



**Annabelle's  
Challenge**

**ANNUAL REPORT AND ACCOUNTS  
FOR THE YEAR ENDING 31<sup>st</sup> MARCH 2023**

**Vascular EDS**

**Our Challenge To Find Your Cure**

Charity Registration No. 1157074



## Structure, Governance and Management

Names of Charity Trustees	David Catterall DL Bonnie Jackson Andy Fish Megan Thornton-Thompson Christina Fallows (Appointed 1 <sup>st</sup> March 2023) Clare Edge (Appointed 1 <sup>st</sup> October 2023) Jack Harris (Resigned 11 <sup>th</sup> September 2023) Kate Manku (Resigned 28 <sup>th</sup> September 2023) Bonnie Jackson (Resigned 11 <sup>th</sup> September 2023)
Charity Registration Number	1157074
Registered	16 <sup>th</sup> May 2014
Registered Office	Annabelle's Challenge Walshaw Park House Walshaw Road, Bury BL8 1PY
Independent Examiner	Peter Nicol FCA Horsfield & Smith Tower House 269 Walmersley Road, Bury BL9 6NX
Bankers	NatWest Virgin

Annabelle's Challenge gained charity status on the 16<sup>th</sup> May 2014 and is a Charitable Incorporated Organisation (CIO) governed by its constitution dated 11<sup>th</sup> March 2014 by a board of trustees.

The trustees delegate the day-to-day running of the charity to the founder & CEO Jared Griffin who in turn gains input from all trustees on major decision-making. Regular communication is maintained with all trustees.

The charity is managed by the trustee body and decisions carried with a majority vote. The trustees pay due regard to the Charity Commission guidance on public benefit in deciding what activities the charity should undertake.

The trustees have assessed the major risks to which the charity is exposed and are satisfied that systems are in place to mitigate exposure to the major risks. The charity is covered by £5,000,000 public liability and employers' liability insurance with Zurich.

The annual report was approved by the trustees of the charity on 30/01/24 and signed on its behalf by:

David Catterall DL  
Chairperson

## Annabelle's Challenge Vascular EDS Charity



Annabelle's Challenge aims to promote awareness and medical research into Vascular Ehlers-Danlos Syndrome (vascular EDS).

The charity was founded in 2013 by Jared and Sarah Griffin, after their daughter Annabelle was diagnosed with vascular EDS at the age of 3. We provide support to children and adults touched by vascular EDS (vEDS).

Vascular EDS is thought to affect around 740 people in the UK, it is a connective tissue disorder and means patients are at daily risk of their internal organs and arteries spontaneously rupturing.

Vascular EDS is a life-threatening connective tissue disorder that affects all tissues, arteries and internal organs making them extremely fragile. Patients are at risk of sudden arterial or organ rupture. Vascular EDS (previously known as Ehlers-Danlos type IV) is a rare type of Ehlers-Danlos syndrome caused by an alteration, also known as a mutation in the COL3A1 gene.

COL3A1 gene is the instruction for making collagen type III a tough fibre-like protein that makes up a third of our body protein. When this gene is altered, it causes a lack or deficiency of this collagen making the connective tissue less effective, particularly in skin, lung, uterus, intestine and the vascular system.

At present, the life span for affected individuals is a median age of about 51 years (49 for males and 53 for females) but with a very large range from 10 years to 80 years. The prevalence is estimated as 1/50,000 to 1/200,000. It is suggested 740 people in the UK have vascular EDS.

## Our Objectives

### EDUCATION

To advance the education of the general public and medical profession in all areas relating to vascular EDS.

### RESEARCH

The relief of sickness and preservation and protection of good health by the provision of funding for the development of research and early diagnosis of vascular EDS.

### SUPPORT

To promote and protect the physical and good mental health of sufferers of vascular EDS, their families, and carers through the provision of financial assistance, support, education, and practical advice.

## Our Charity

- Provides information, leaflets, advice and a VEDS support programme.
- Currently has over 370 members who have been diagnosed with the condition.
- Has a website, Facebook, Twitter, and Instagram page.
- Organises events to raise awareness and raise funds.
- Produces newsletters, emails, and updates to current members.
- Works closely with the NHS EDS National Diagnostic Service.
- Collaborates with The Ehlers-Danlos Support UK charity.
- Raises awareness through media, organised events, sponsorship, and networking.
- Provides free MedicAlert UK membership & exclusive discounts.
- Has a dedicated freephone helpline service and patient coordinators.
- Provides conferences and retreat weekends
- Hosts the annual REDS4VEDS global awareness campaign.
- Funds Research.





## Achievements and Performance

Most people who contact Annabelle's Challenge require information and support. We provide first-hand experience and advice to those who need emotional support especially with coping and adjusting to an uncertain future living with vascular EDS.

The charity works closely with the EDS National Diagnostic Service, a highly specialised service commissioned by NHS England and receives patient referrals to enable us to support individuals and families touched by vascular EDS. Membership is free and continues to grow and we now support over 370 members.

Our weekly e-newsletter had an open rate of 51.1%, we recognise that not all our members are on social media and will continue to use this resource to communicate with our subscribed members. Social media continues to grow with 6,029 Facebook, 2,886 Twitter and 1,520 Instagram followers.

As a small charity for a rare genetic disorder, we need to amplify our voice and continue to work with Genetic Alliance UK and Gene People. We work with Beacon and are also proud stakeholders in the VEDS Collaborative Group in the US.



The charity is an official partner with MedicAlert UK enabling us to offer free medic alert membership and discounts on medic alert jewellery exclusive to our vascular EDS members. We continue to raise awareness for research into vascular EDS and have a restricted fund and a designated fund available for future research projects.

We are also delighted and honoured to receive a Community Champion Award from Ehlers-Danlos Support UK.



## VEDS Support Programme

Our VEDS Support Programme is available to all our members touched by vascular EDS and offers advocacy, emotional and practical support. From the moment someone joins Annabelle's Challenge they will have free access to all our resources and advice:

- VEDS management guidance.
- Emergency preparedness.
- Talks and support in educational settings.
- Peer support 'buddy up' with other vascular EDS members.
- Vascular EDS Retreat Weekends, Conferences & Events.
- Patient Coordinator support.
- Freephone helpline.
- Online support and 1-2-1 calls.
- Free Sunflower lanyard and EDS awareness card.
- Help with creating a care team.
- Access to research study projects & clinical trials.
- Access to private Facebook support groups.
- Ambulance Medical Marker requests.
- Mental Health First Aid support.
- Free MedicAlert UK, Ireland & Australia subscription plus exclusive discounts on bracelets.
- Regional Support Groups.





## VEDS Steering Group

The VEDS Steering Group will help to shape the future of the charity as it continues to grow providing support, guidance and overseeing the progress of all community-based projects including events and research in the UK.

The VEDS Steering Group is made up of volunteers who are directly touched by vEDS including patients, parents and carers, they are supported by genetic counsellors from the EDS National Diagnostic Service with representation from both clinics based in Sheffield and London.

### Steering group aims:

- Provide input based on their direct experience of vEDS.
- Give strategic direction.
- Support the charity.
- Enable more people diagnosed with vEDS to fulfil their potential by working to address issues at the earliest possible stage through the VEDS Support Programme.

The steering group usually meets at key stages during the course of a project and influences strategic decisions including reviewing and advising on vEDS research proposals.

## VEDS Regional Support Groups



Our regional support groups across the UK are for those who are touched by vascular EDS and all family members are welcome to attend.

The groups are managed by our volunteer regional coordinators creating a safe, relaxed environment where people can share experiences, advice and provide peer support creating life-long friendships with others.

Our patient coordinators work closely with the volunteer area coordinators to help plan suitable venues and logistics across the UK.







## Queen's Award for Voluntary Service



Annabelle's Challenge are proud recipients of **The Queen's Award for Voluntary Service**. The unique UK national honour was created by Her Majesty to mark the Golden Jubilee in 2002 and to recognise the outstanding contributions made to local communities by groups of volunteers.

The award is equivalent to the MBE and is the highest award that can be made to a voluntary group.

Our founders Jared and Sarah received an invitation to attend a Buckingham Palace garden party hosted by Her Majesty The Queen and members of the royal family.

Jared "We are so proud to receive the Queen's Award on behalf of all our volunteers who support the important work we do for patients and families touched by vascular EDS, receiving this award is a real morale booster recognising the work of the volunteers."

Annabelle's Challenge is among 27 other volunteer groups in the county to receive the award with 250 nationally announced on 2<sup>nd</sup> June 2018.

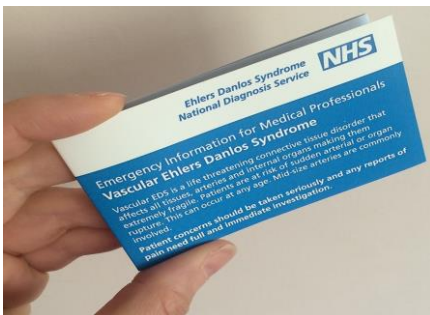






We are proud to work closely with the Ehlers-Danlos Syndrome National Diagnostic Service, a highly specialised service commissioned by NHS England for individuals and families who are suspected to have complex Ehlers-Danlos Syndrome (EDS).

Established in 2009 the service runs two specialist clinics for patients at Sheffield Northern General Hospital and the Northwick Park & St Mark's Hospitals in London.



## The aims of the service

- Correctly investigate and diagnose cases of suspected rare EDS types. DNA analysis mainly currently in Sheffield lab.
- Develop guidelines and pathways of care for the different subtypes of EDS.
- Provide information about EDS for patients and their carers.
- Research regarding rare types of EDS.

They provide an excellent diagnostic service for adults and children with suspected complex EDS and strive to incorporate new diagnostic techniques and developments in their practice.

Referrals are accepted from NHS Consultants in Secondary or Tertiary care for both adults and children.

- The service sees patients who are suspected of having a diagnosis of classical, vascular or a rare type of EDS. The service will also see patients with a known diagnosis of classical, vascular or a rare type of EDS.
- Patients with hypermobile EDS or Hypermobility Spectrum Disorder are not seen in this clinic.
- The clinic does not offer management for hypermobility.



Established in 2009



Sheffield & London



Genetic Counselling



Diagnostic Service



## Financial Review

The accounts for the year ending 31<sup>st</sup> March 2023 shows a surplus of £33,386 and total funds carried forward of £204,710. We need to ensure our reserve policy is sustainable and provide the required funds to provide support for patients and families, and increase designated funds for future research into vascular EDS.

The fundraising by our members and supporters has gone extremely well with a total voluntary income of £70,179 and we are grateful to all our volunteers, members, and fundraisers for supporting the charity.

We are now in a strong position to fund future vital research into vascular EDS with £100,000 designated in reserves.

## Reserves Policy

The trustees have reviewed the reserves of the charity. Our aim is to maintain reserves in unrestricted funds at a level of £18,000 to cover operational, support costs and unforeseen expenditure over at least a 6-month period.

## Safeguarding Policy

This policy applies to anyone working on behalf of Annabelle's Challenge including senior managers, board of trustees, paid staff, volunteers and students.

- to protect children and adults who receive support from Annabelle's Challenge.
- to provide parents, staff and volunteers with the overarching principles that guide our approach to child protection and safeguarding for children and adults.

## Privacy Policy

We take privacy very seriously. For that reason, we have set out a privacy policy, so patients and families can make sure they understand how and why we use the information they give us. The charity is also registered with the Information Commissioners Office (ICO) number ZA450659.



## Equality & Diversity Policy



Annabelle's Challenge is an equal opportunity charity taking into account the diversity within our community, staff, members and volunteers.

We believe that everyone should be treated equally, regardless of their religion, beliefs, age, gender, race, disability or sexual orientation.

The Equality & Diversity Policy requires commitment from everyone within the Charity. Our Founder, Jared Griffin, is responsible for the implementation and effective operation of this policy.

## Fundraising Promise

This promise outlines the commitment made to our donors and the public when fundraising and we are registered with the Fundraising Regulator. We agree to ensure our fundraising is legal, open, honest and respectful. The standards for fundraising are set out in the Code of Fundraising Practice.







## VEDS Conference

We were delighted and super proud to have hosted VEDS Conference 2022 with Ehlers-Danlos Support UK and the EDS National Diagnostic Service at the Village Hotel Club Bury.

200 delegates attended including 65 VEDS children and adults for a weekend of fun, positivity and hope!

Guest speakers provided updates on VEDS management, genetics, research, future clinical trials, patient experiences and advocacy plus the importance of keeping mentally healthy.







## How we spent money raised

100% of all funds raised directly helps our charity to carry out its objectives for the public benefit. As a small UK charity, we do not receive any NHS funding and rely on public donations and grant funding to help us raise awareness and provide essential support to families touched by vascular EDS.

We spent a total of £117,592 on charitable activities including the delivery of our VEDS Support Programme and the following projects and support costs:

- |                                      |         |
|--------------------------------------|---------|
| • Staff Training                     | £250    |
| • MedicAlert memberships             | £534    |
| • VEDS Support Groups                | £1,658  |
| • Office costs                       | £7,491  |
| • Postage and stationery             | £1,814  |
| • Travel UK & International          | £5,947  |
| • Website, Telephone & Internet      | £2,093  |
| • Family Retreat Weekends            | £24,495 |
| • VEDS Conference                    | £17,138 |
| • Salaries including PAYE & Pensions | £55,029 |

# ANNUAL ACCOUNTS FOR YEAR ENDING 31st MARCH 2023

Statement of Financial Activities	Notes	Unrestricted Funds	Designated Funds	Restricted Funds	Total Funds	Last Year
		£	£	£	£	£
<b>Incoming Resources</b>						
<b>Incoming resources from generated funds</b>						
Voluntary Income (Notes 1)		20,179.46	50,000.00		70,179.46	93,530.39
Activities for generating funds		5,563.32			5,563.32	2,228.78
Gross Trading		2,785.88			2,785.88	3,108.00
Gift Aid		6,692.00			6,692.00	5,515.64
Grants (Notes 2)		4,338.85		67,906.75	72,245.60	61,278.50
<b>Total Incoming Resources</b>		39,559.51	50,000.00	67,906.75	157,466.26	165,661.31
<b>Resources Expended</b>						
<b>Costs of generating funds</b>						
Expenses for fundraising activities		748.26			748.26	2,469.29
Gross trading payments		2,373.58			2,373.58	3,291.64
Charitable Activities		47,009.58		70,582.61	117,592.19	53,795.62
Grants						2,167.50
Governance Costs		3,116.31		250.00	3,366.31	2,702.57
<b>Total Resources Expended</b>		53,247.73		70,832.61	124,080.34	64,426.62
<b>Net income for the year before transfers</b>		(13,688.22)	50,000.00	(2,925.86)	33,385.92	101,234.69
<b>Total Funds brought forward</b>		65,517.60	50,000.00	56,115.51	171,323.91	70,089.22
<b>Total funds carried forward</b>		51,829.38	100,000.00	53,189.65	204,709.83	171,323.91

All of the charity's activities are classed as continuing

(1) Designated funds are allocated for Vascular EDS research either current, planned or invited.

(2) Grants:

Unrestricted funds – Jeans For Genes	340.00
Unrestricted funds – Aytu BioPharma sponsorship	3,998.85
Restricted funds - EDS Support UK	8,967.75
Restricted funds - The National Lottery Community Fund	58,939.00
	<u>72,245.60</u>

## Benefits and payments to charity trustees and connected persons

No trustees have received any reimbursed expenses or any other benefits from the charity during the year.



# Balance Sheet

	Notes	Unrestricted Funds	Designated Funds	Restricted Funds	Total Funds	Last Year
<b>Fixed Assets</b>		£		£	£	£
Tangible Assets		3,742.11			3,742.11	4,201.07
Investments						-
<b>Total fixed assets</b>		3,742.11			3,742.11	4,201.07
<b>Current Assets</b>						
Other debtors		-	-	-	-	-
Prepayments		-	-	-	-	-
Cash in Bank						
NatWest		41,908.83	50,000.00	47,346.58	139,255.41	106,476.73
PayPal		743.41	-	-	743.41	512,.31
Virgin Reserve		5,435.03	50,000.00	5,842.97	61,278.00	60,443.00
<b>Total Current Assets</b>		48,087.27	100,000.00	53,189.55	201,276.82	167,432.04
<b>Current Liabilities</b>						
Other creditors		-	-	-	-	-
<b>Net Current Assets</b>		48,087.27	100,000.00	53,189.55	201,276.82	167,432.04
<b>Net Assets</b>		51,829.38	100,000.00	53,189.55	205,018.93	171,323.91
<b>Funds of the Charity</b>						
Unrestricted Funds					151,829.38	115,208.40
Restricted Funds					53,189.55	56,115.51
<b>Total Funds</b>					205,018.93	171,323.91

Signed on behalf of all the trustees

Signature

Name

Date

David  
Catterall

Chairperson

30/01/2024





# ANNABELLE'S CHALLENGE

## INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF ANNABELLE'S CHALLENGE

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I report to the charity trustees on my examination of the accounts of the charity for the year ended 31 March 2023.

### **Respective responsibilities of trustees and examiner**

As the charity's trustees of Annabelle's Challenge, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Annabelle's Challenge's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

### **Independent examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of Annabelle's Challenge as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Peter Nicol FCA  
Independent examiner

Tower House  
269 Walmersley Road  
Bury  
Lancashire  
BL9 6NX

Date: 30<sup>th</sup> January 2024





**The Queen's Award  
for Voluntary Service**



# Thank You!

Thank you to our members, volunteers, trustees, fundraisers,  
and donors for continuing to support Annabelle's Challenge.

