



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



# Annabelle's Challenge

**ANNUAL REPORT AND ACCOUNTS  
FOR THE YEAR ENDING 31<sup>st</sup> MARCH 2024**

## **Vascular EDS**

**Our Challenge To Find Your Cure**

Charity Registration No. 1157074

# Celebrating 10 Years!

## 2013 - 2023



## Structure, Governance and Management

|                             |  |
|-----------------------------|--|
| Names of Charity Trustees   | David Catterall DL<br>Andy Fish<br>Megan-Thornton-Thompson<br>Christina Fallows<br>Clare Edge    |
| Charity Registration Number | 1157074  |
| Registered                  | 16 <sup>th</sup> May 2014  |
| Registered Office           | Annabelle's Challenge<br>Walshaw Park House<br>Walshaw Road, Bury<br>BL8 1PY                     |
| Independent Examiner        | Jonathan Staples FCA<br>Horsfield & Smith<br>Tower House<br>269 Walmersley Road, Bury<br>BL9 6NX |
| Bankers                     | NatWest<br>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 30/01/2025 and signed on its behalf by:

David Catterall DL  
Chairperson

## Annabelle's Challenge Vascular EDS Charity



Annabelle's Challenge is the leading charity for vascular Ehlers-Danlos Syndrome (vascular EDS) in the UK and proud recipients of The Queen's Award for Voluntary Service.

At the heart of the charity is Annabelle who is the inspiration behind our challenge to provide education, research and support for patients and families affected by vascular EDS.

The charity was founded in 2013 by Jared and Sarah Griffin shortly after their daughter Annabelle was diagnosed at the age of 3, at that time she was the youngest in the UK to be diagnosed with vascular EDS.

Vascular EDS (vEDS) is a connective tissue disorder that affects all tissues, arteries and internal organs making them extremely fragile. Patients are at daily risk of sudden arterial or organ rupture and it is thought to affect around 740 people in the UK.

Vascular EDS can be very variable even within the same family. It is also rare and therefore many health professionals will not have seen someone with this diagnosis. With the correct precautions in place, people can live very long lives with vascular EDS (Our database has of 70/80+ years old).

### 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.

### How we support the vEDS community

Most people who contact Annabelle's Challenge require information and support. We provide first-hand lived experience and advice to those who need support including:

- Free family, lifetime membership.
- Access to our VEDS Support Programme.
- School and Nursery guidance and support.
- Information via our website, Facebook, X, and Instagram pages.
- Weekly newsletters, emails, and updates.
- Free MedicAlert UK membership & exclusive discounts.
- Dedicated freephone helpline service, supported by our patient coordinators.
- Conferences and retreat weekends.
- Free, confidential Counselling Service.
- Access to research and clinical trials.





## Achievements and Performance

Thanks to our members, donors and The National Lottery we have raised £239,263 this year and we are well on track to achieve the £1,000,000 milestone way ahead of our planned Vision 2025 goal.

Over the past 12 months we announced 5 new research projects, hosted 2 vEDS retreat weekends, 9 vEDS support groups, launched a new Counselling Service and a new VEDS Emergency Information Pack. We also welcomed 69 new members representing 76 patients.

Annabelle's Challenge now has 539 patients registered on the database across 22 countries, we also celebrated 10 years since we launched in January 2013.

It has been super busy for the team in delivering the VEDS Support Programme thanks to National Lottery funding. The charity supports over 440 members touched by vascular EDS, since the support programme was launched in August 2021, we have recruited new Patient Coordinators and together Team AC have so far achieved:

- ✓ 44 x School & Nursery visits
- ✓ 101 x Medic Alerts
- ✓ 134 x EDS Sunflower Lanyards
- ✓ 143 x Ambulance Markers
- ✓ 248 x VEDS Emergency Information Packs
- ✓ Mental Health First Aid accredited by MHFA England
- ✓ Community Champion award by EDS Support UK





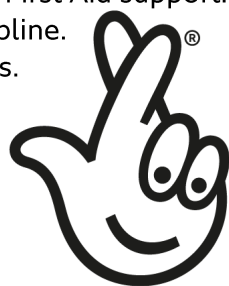


## VEDS Support Programme

The VEDS Support Programme is a project funded by The National Lottery Community Fund and is available to all members touched by vascular EDS, providing advocacy, emotional and practical support.

From the moment someone joins Annabelle's Challenge they will have free access to all our resources and advice, membership is free:

- VEDS management guidance.
- Emergency preparedness.
- Free, confidential Counselling Service.
- Talks and support in educational settings.
- Peer support with other vascular EDS members.
- VEDS Retreat Weekends, Conferences & Events.
- Patient Coordinator support.
- Free MedicAlert UK subscription
- Online support and 1-2-1 calls.
- Free Sunflower lanyard and vEDS awareness card.
- Help with creating a care team.
- Access to research study projects & clinical trials.
- Access to private Facebook support groups.
- Ambulance Marker requests.
- Exclusive Careline365 discount on SOS GPS alarms.
- Mental Health First Aid support.
- Freephone helpline.
- Support Groups.



**COMMUNITY  
FUND**





## 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 and an ICC Advanced Nurse Practitioner.

### 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.

## 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 regional coordinators to help plan suitable venues and logistics across the UK.





## Board of Trustees



**David Catterall DL**  
Chairperson

David took up the role of trustee and chairperson of Annabelle's Challenge in May 2022.

He is a champion of the LGBTQI+ community in Bury and has built up a successful career at Bury Council and is now Head of Commercial Services.

As well as being involved in supporting the LGBTQI+ community in Bury and Greater Manchester, he co-founded the Bury LGBTQI+ Forum, a charity which supports LGBTQI+ people and helps organisations to be inclusive. He has been instrumental in driving and leading Bury Pride to become the UK's best small pride event in 2021.

David was made a Deputy Lieutenant of Greater Manchester in March 2022.



**Meg Thornton-Thompson**  
Trustee

Hi, I'm Meg. Followers of Annabelle's Challenge may know me as the lady behind the camera as I've been the AC photographer since meeting Jared, Sarah and Annabelle in 2016. I started my photography business back in 2013 specialising in weddings, events and commercial products.

I am a qualified Occupational Therapist. I also have a background in Child and Adolescent Mental Health Services (CAMHS) supporting young people with their recovery and mental health journey.

Being at each of the events, fundraisers and the vEDS conferences, I have seen up close the impact vEDS has on individuals and families, and I'm honoured to have a more substantial role within Annabelle's Challenge in helping them raise awareness and funds to support the vEDS community and further research.



**Andy Fish**  
Trustee

Andy is a Chartered Accountant qualifying in 1993. He has spent his career working in the hospitality industry currently as the Chief Financial Officer of the Yotel hotel group.

Andy's son was diagnosed with vEDS in 2005 and his wife Jacqui volunteers for the charity as the area coordinator for South East England.



**Christina Fallows**  
Trustee

Christina joined Annabelle's Challenge in 2013 as a volunteer before taking up the role of patient coordinator in 2019, a role she held for 3 years helping to shape the future of the charity and securing vital funding from The National Lottery.

"In August 2019 I was delighted to take on the new role as the patient coordinator for the charity to help support all our members both existing and newly diagnosed. My role included managing the vEDS database, providing support & advice, supporting the CEO and facilitating referrals to our EDS clinics in Sheffield & London. I am also a Mental Health First Aider accredited by MHFA England."

Christina has a first class honours in Psychology and is currently a school support worker. She joined the board of trustees on 1st March 2023.



**Clare Edge**  
Trustee

Clare joined Annabelle's Challenge in December 2018 and has now taken on the role of trustee on the Annabelle's Challenge board effective from 1st October 2023. Prior to her appointment to the board of trustees Clare was a member of the vEDS Steering Group. Her son was diagnosed with vascular EDS in 2007.

Clare is a senior sales consultant at Oxford University Press and also a trustee for the Walk and Talk Trust.

Previous roles include sales and a flight attendant at Virgin Atlantic and Saudi Arabian Airlines.

## Regional Coordinators



**Linda Clamp**  
Scotland



**Sophie Leftley**  
Yorkshire & Humber



**Claire Hall**  
East Anglia



**Taylor Barlow**  
South West



**Gemma Hasnaoui**  
South West



**Jacqui Fish**  
South East



**Peter Black**  
North East



**Bonnie Jackson**  
London



**Lynda Allen**  
Wales



**Danika Davidson**  
North West



**Scarlett Thomas**  
Ireland & Northern Ireland



**Jared Griffin**  
East & West Midlands





## 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.

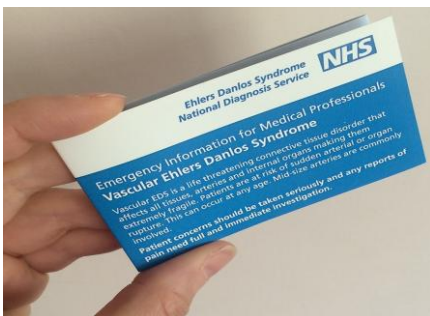






We are proud to work closely with the Ehlers-Danlos Syndrome National Diagnostic Service, a highly specialised service commissioned by NHS England for individuals and families who are suspected to have complex Ehlers-Danlos Syndrome (EDS).

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 2024 shows a surplus of £110,544 and total funds carried forward of £315,563, this includes a grant payment of £61,586 from The National Lottery towards the VEDS Support Programme.

The fundraising by our members and supporters has again gone extremely well with a total voluntary income of £162,949 (up from £70,179 the previous year). We are grateful everyone who have supported us during these challenging times.

Annabelle's Challenge is currently in a good financial position with the funds carried over to fund future research! Of the amount carried forward £182,000 is designated to research and we are pleased to confirm we have received two research proposals.

## 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 3-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 and access our services.
- 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 and our 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.







## Blackpool Retreat Weekend

We were delighted to welcome 105 of our members to the VEDS Retreat Weekend in the North of England, which took place at The Cliffs Hotel in Blackpool Friday 1st - Sunday 3rd December, 2023.

"It was so nice to have a rest, enjoy time together as a family and see and show the children they are not alone."

"I would like to say a really big heartfelt THANK YOU for such a lovely, enriching retreat weekend in Blackpool. It was so generous and kind of you. It felt strangely comforting being around others with a shared understanding and experience of the condition."

"Thank you all for organising the retreat for us all. It brought all of my family together, which doesn't happen very often and we all had a fabulous time and took away some great new memories."

The retreat weekend was an all-inclusive stay at The Cliffs with lots of free time for our members to meet each other and make life-long friends.







**WEAR  
RED**



**TAKE A  
PHOTO**



**SHARE  
IT**

Wear something red, take a photo & share it on your social media using the hashtag

**#REDS4VEDS**

## REDS4VEDS

REDS4VEDS Day takes place on the **third Friday of May** with supporters and followers wearing red to raise awareness of vascular EDS across the globe.

Using the hashtag **#REDS4VEDS** news feeds turned red worldwide and is now an annual awareness campaign hosted by Annabelle's Challenge.

Following a successful launch in May 2015 the annual campaign now raises vital funds towards research and supporting families touched by vascular EDS.



**Reds4Veds Day  
19th May 2023**



**#REDS4VEDS**





400

VEDS PATIENTS



1 - 88

AGE RANGE

## 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 members touched by vascular EDS.

We spent a total of £115,746 on charitable activities which included the cost of delivering the VEDS Support Programme. The following projects, events and operational costs include:

|                                    |         |
|------------------------------------|---------|
| • Small Grants                     | £723    |
| • Staff Training                   | £786    |
| • MedicAlert memberships           | £1,380  |
| • Website, Telephone and Internet  | £2,093  |
| • Postage and stationery           | £2,552  |
| • Travel for awareness & education | £4,619  |
| • Support Groups                   | £4,633  |
| • Counselling Service              | £6,105  |
| • Office costs                     | £7,371  |
| • Retreat Weekends                 | £21,379 |
| • Salaries incl PAYE & Pensions    | £62,604 |



## Plans for Future Period

We are in a strong position to further enhance the support we provide to our members touched by vascular EDS, over the next 12 months we aim to increase the number of support groups taking place in-person and online and host another retreat weekend in Devon.

Working with The Ehlers Danlos Support UK a conference is currently being planned for 2025, our third conference for vascular EDS patients and families supported by the EDS Service.

A designated fund of £182,000 for future research projects is now available, currently two research projects have been submitted to the charity for consideration with a projected start date during 2025.

- 👉 Plan for VEDS Conference 2025.
- 👉 Launch new publications in journals.
- 👉 Update EDS Sunflower Lanyards.
- 👉 Provide results of the annual members survey.
- 👉 Announce new online vEDS support groups.
- 👉 Increase the number of vEDS in-person support groups.
- 👉 Announce new research projects.
- 👉 Commission new information videos through the Emergency Care Project team.
- 👉 Jointly host an international symposium patient day with The Marfan Foundation.
- 👉 Fundraise to increase funds designated for research.
- 👉 Invest in new IT, telecoms and cyber security.
- 👉 Continue to collaborate with other charities, organisations and community groups.





# ANNUAL ACCOUNTS FOR YEAR ENDING 31st MARCH 2024

| 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)                      |       | 62,949.23          | 100,000.00       |                  | 162,949.23  | 70,179.46  |
| Activities for generating funds                 |       | 3,546.74           |                  |                  | 3,546.74    | 5,563.32   |
| Gross Trading                                   |       | 3,818.98           |                  |                  | 3,818.98    | 2,785.88   |
| Gift Aid  |       | 6,654.41           |                  |                  | 6,654.41    | 6,692.00   |
| Interest received                               |       | 437.88             |                  |                  | 437.88      |            |
| Grants (Notes 2)                                |       |                    |                  | 61,856.00        | 61,856.00   | 72,245.60  |
| <b>Total Incoming Resources</b>                 |       | 77,407.24          | 100,000.00       | 61,856.00        | 239,263.24  | 157,466.26 |
| <b>Resources Expended</b>                       |       |                    |                  |                  |             |            |
| <b>Costs of generating funds</b>                |       |                    |                  |                  |             |            |
| Expenses for fundraising activities             |       | 7,339.92           |                  |                  | 7,339.92    | 748.26     |
| Gross trading payments                          |       | 2,190.62           |                  |                  | 2,190.62    | 2,373.58   |
| Charitable Activities                           |       | 45,878.67          |                  | 69,867.40        | 115,746.07  | 117,592.19 |
| Grants  |       |                    |                  |                  |             |            |
| Governance Costs                                |       | 3,442.79           |                  |                  | 3,442.79    | 3,366.31   |
| <b>Total Resources Expended</b>                 |       | 58,852.00          |                  | 69,867.40        | 128,719.40  | 124,080.34 |
| <b>Net income for the year before transfers</b> |       | 18,555.24          | 100,000.00       | (8,011.40)       | 110,543.84  | 33,385.92  |
| <b>Total Funds brought forward</b>              |       | 51,829.38          | 100,000.00       | 53,189.55        | 205,018.93  | 171,633.01 |
| <b>Total funds carried forward</b>              |       | 70,384.62          | 200,000.00       | 45,178.15        | 315,562.77  | 205,018.93 |

All of the charity's activities are classed as continuing.

(1) Designated funds:  
 Research fund; either current, planned or invited 182,000.00  
 Operating fund 18,000.00

(2) Restricted funds:  
 Grant - The National Lottery Community Fund 61,856.00

## Benefits and payments to charity trustees and connected persons

# Balance Sheet

|                             | Notes | Unrestricted Funds | Designated Funds | Restricted Funds | Total Funds | Last Year  |
|-----------------------------|-------|--------------------|------------------|------------------|-------------|------------|
| <b>Fixed Assets</b>         |       | £                  |                  | £                | £           | £          |
| Tangible Assets             |       | 4,829.82           |                  |                  | 4,829.82    | 3,742.11   |
| Investments                 |       |                    |                  |                  |             | -          |
| <b>Total fixed assets</b>   |       | 4,829.82           |                  |                  | 4,829.82    | 3,742.11   |
| <b>Current Assets</b>       |       |                    |                  |                  |             |            |
| Other debtors               |       | -                  | -                | -                | -           | -          |
| Prepayments                 |       | -                  | -                | -                | -           | -          |
| Cash in Bank                |       |                    |                  |                  |             |            |
| NatWest                     |       | 57,374.23          | 150,000.00       | 39,335.18        | 246,709.41  | 139,255.41 |
| PayPal                      |       | 2,259.43           | -                | -                | 2,259.43    | 743.41     |
| Virgin Reserve              |       | 5,921.14           | 50,000.00        | 5,842.97         | 61,764.11   | 61,278.00  |
| <b>Total Current Assets</b> |       | 65,554.80          | 200,000.00       | 45,178.15        | 310,732.95  | 201,276.82 |
| <b>Current Liabilities</b>  |       |                    |                  |                  |             |            |
| Other creditors             |       | -                  | -                | -                | -           | -          |
| <b>Net Current Assets</b>   |       | 65,554.80          | 200,000.00       | 45,178.15        | 310,732.95  | 201,276.82 |
| <b>Net Assets</b>           |       | 70,384.62          | 200,000.00       | 45,178.15        | 315,562.77  | 205,018.93 |

## Funds of the Charity

|                    |                   |                   |
|--------------------|-------------------|-------------------|
| Unrestricted Funds | 70,384.62         | 51,829.38         |
| Designated Funds   | 200,000.00        | 100,000.00        |
| Restricted Funds   | 45,178.15         | 53,189.55         |
| <b>Total Funds</b> | <b>315,562.77</b> | <b>205,018.93</b> |

Signed on behalf of all the trustees

Signature



Name

David  
Catterall

Date

Chairperson 30/01/2025



## 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 2024.

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

As the charity 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 2025





Celebrating 10 Years!

Thank You!

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

