Annual Report

Year ending
31st December 2025



usherkidsuk

usherkidsuk.org

Chair's welcome



Our annual report offers an opportunity to reflect and celebrate the achievements and progress made by Usher Kids UK in 2025.

Our community has grown as we welcomed newly-diagnosed children, young people and families, and as we introduced new programmes tailored to the specific needs and priorities of different age groups.

Our small team can be proud of the services they deliver, which are changing the experiences and outcomes for the next generation living with Usher syndrome. We extend our sincere and heartfelt thanks to each and every supporter and partner, every community member, trustee and volunteer: your support helps this community to thrive.

Chloe Joyner, Chair of trustees

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Our mission and values



Our vision is a world in which every person with Usher syndrome thrives.

Our mission is to empower children, young people and their families living with Usher syndrome in the UK, through the provision of connections, information, support and advocacy.

Our values

We are inclusive: We champion a community where everyone is seen, heard, and valued. We always reflect the voices of our community.

We are collaborative: We value partnerships and share knowledge to empower and support our community.

We have integrity: We uphold the highest professional and ethical standards to inspire trust and confidence from our community.

We are focused: We are focused on the unique experience and priorities of children, young people and families with Usher syndrome.

Our strategic objectives



Connections

We create opportunities for our community to share experiences and meet others who understand.



Information

We create trusted resources through collaboration with experts, tailored for our community of families and professionals.



Support

Wherever you are in your journey, we are here with support for you and your family.



Advocacy

We harness insight from our community to amplify their voice, champion their priorities and improve outcomes.

Our people



Our Chief Executive Officer

Emma King leads delivery of our work in empowering children, young people and families with Usher syndrome, drawing upon her background in education and charity leadership.



Our Events & Communications Lead

Jessica Hill helps plan and deliver our programme of events, leads our social media channels and supports engagement within our community, creating welcoming and inclusive opportunities to connect.



Our Family Liaison Officer

Penny Lockhart joined the team in April 2025 to support families from diagnosis onwards. She works closely with both parents and carers, and children and young people, making sure everyone feels empowered and understood.



Our Chair of Trustees

Chloe Joyner founded Usher Kids UK in 2017, and continues to provide strategic input in her role as Chair of Trustees.

Section 2:
Our activities and highlights

The following pages feature a spotlight on some of our key services in 2025. While not an exhaustive overview of our work, they illustrate the range and impact of support we provide to our community.

Empower Ush

Supporting young adults with Usher syndrome to thrive.

In 2025, we launched Empower Ush, a new pilot programme supporting young adults aged 17–25 with Usher syndrome to build confidence, independence and connection as they navigate early adulthood. The pilot ran over eight months, with the first phase dedicated to co-designing the programme alongside young adults to ensure it reflected their needs, priorities and lived experiences.

This collaborative approach shaped all aspects of delivery. Through personalised mentoring, peer connection and practical support, participants developed the skills, knowledge and self-belief to take meaningful steps towards their goals.



> ***Empower Ush has been amazing! They have helped me find the path for a future career which was one of my goals and I can't believe I now have an idea on what I want to do future career wise and I wouldn't of been able to do that without this programme!***
>
> *21yr old participant*

The pilot year of Empower Ush has shown the power of combining personalised support with community connection - helping young adults to grow in confidence, build independence and shape their futures.

Empower Ush: Impact in 2025

6 young adults aged 17-25yrs took part in the pilot programme

12 one-to-one support sessions delivered

25 event attendances, including virtual sessions and an in-person residential



29 connections made with organisations and professionals

What the programme delivered:

- Personalised 1:1 mentoring and goal setting
- Support to develop independent life skills
- Regular peer connection and group sessions
- Access to specialist organisations and services
- Access to free talking therapy with a specialist counsellor
- Opportunities to build self-advocacy and identity

What changed as a result of Empower Ush:

Across the first six months, participants reported:



Engagement
Increased engagement in social, peer and advocacy opportunities



Confidence
Increased confidence in managing adult life skills and planning for the future



Wellbeing
Positive and sustained wellbeing, with many reporting improvements across key measures



Personal goals
Greater confidence in taking steps towards personal goals

Participants commonly progressed from neutral to agree or strongly agree across confidence, independence and connection measures.

> ***Empower Ush has connected me with other young adults who are navigating the same stage of life, which has made me feel less alone. It's given me practical support with my Usher syndrome, from learning how to budget to booking passenger assist, helping me build confidence in managing everyday challenges. I feel understood and supported.***
> *Young adult aged 20*

> ***This programme has helped me gain the confidence to do more than I ever thought possible. It has made a lasting impact on my independence, sense of community, and pride in my identity and story, which is something that every young adult deserves to feel.***
> *Adult participant*

We are extremely grateful to ***Fight for Sight*** for funding this programme through their Social Change Fund, making this pilot possible.

Empower Ush: Case study

Evie's story:

Building independence and confidence

Evie, aged 19, joined Empower Ush with clear ambitions for her future and chose to focus on building independent travel skills. With tailored one-to-one support from Usher Kids UK including a referral for specialist training, she developed practical travel planning skills and confidence using public transport.

A major milestone came when Evie travelled over 150 miles independently to attend the Empower Ush residential retreat.

"It was my first big trip using Passenger Assistance without my parents. The staff guided me to the platforms and helped me find my seat, which made the journey smoother."



> ***"Bus training didn't just teach me a route, it gave me independence. Having the skills to travel on my own means I can now go and do whatever I fancy."***
>
> *Evie, 19yrs old*

Empower Ush: Case study

At the retreat, Evie connected with other young adults, building friendships and confidence through shared experience.

She has since completed her travel training and embedded these skills into everyday life.

Evie is continuing to build her independence and explore new opportunities with confidence.

> ***We were all tired but proud. We'd done it — travelled to Cardiff and back on our own, navigated Passenger Assistance, and learned so much along the way.***
>
> *Evie, 19yrs old*



Evie's journey reflects the wider impact of Empower Ush:

- Creating opportunities for connection and shared experience
- Support to take meaningful steps towards their future
- Increasing confidence to take on new challenges
- Building practical independence and life skills

Family support

Supporting families from diagnosis onwards

In 2025, we strengthened and expanded our support for families of children and young people with Usher syndrome. With a growing community and increased demand for support, we built additional capacity in our team while continuing to provide trusted information, connection and personalised support at every stage.

A key milestone in 2025 was welcoming Penny Lockhart as our Family Liaison Officer, significantly increasing our capacity to support families from the point of diagnosis onwards. Penny provides tailored information, emotional support and practical guidance, alongside personalised signposting to specialist services—ensuring families feel informed, supported and empowered at every stage of their journey. At the same time, Jessica Hill, our Events and Communications Lead, played a vital role in increasing the reach of our services—ensuring more families could access support, information and opportunities to connect.

> ***Usher Kids UK have been the single biggest factor in our family accepting, living with, and thriving with Usher syndrome.***
>
> *Parent of child with Usher syndrome*



Family support: Impact in 2025

442 family members supported

171 children and young people in our community



Our offer to families:

- Personalised 1:1 support, information and guidance
- A private Facebook support group for peer connection
- Monthly Ush Chats – virtual support sessions for parents
- Access to expert information and specialist organisations
- Opportunities for in-person connection and shared experiences

Through this combination of support, families are able to access both practical guidance and meaningful connection with others who understand their journey.

Throughout 2025, families connected through a range of events and opportunities

Family Fun Day, bringing families together for shared experiences and connection
Family Info Day, combining expert knowledge with peer support
Virtual support providing ongoing opportunities to connect

Over 100 people joined our family information day, 50% of whom were new to our services, many with a recent diagnosis

What our community tells us about our family support:

"It has been nothing short of life changing for both us as parents in getting vital information and connecting with other parents in the same position, but also our daughter in meeting people who are just like her."

"The impact of this charity is profound. It offers a genuine sense of perspective that simply can't be gained elsewhere."

"Usher Kids UK give us all a sense of community. It greatly enhances my child's confidence and self-belief. It shows us all what is possible."

Our family support ensures that every family has access to the information, connection and support they need - so that no one has to navigate their journey alone.

By combining personalised support, trusted information and opportunities for connection, we are helping families to feel informed, confident and supported from diagnosis onwards.



"Usher Kids creates a sense of belonging. To be with other people that just 'get it'. Always so much information to absorb, but I leave feeling calmer and more empowered."

Parent attendee at Family Info Day

Family support: Case study

One family's journey to feeling informed, connected and empowered

A family contacted Usher Kids UK soon after their child's diagnosis, seeking clear information and connection with others. Through our support, they accessed expert-approved information, one-to-one guidance, and connections with peers through our virtual services.

Reflecting on this early support, the parent shared:

"When we first had the diagnosis... it was good to find out there were other families going through the same thing. It made us feel much more positive and informed."

> ***"The events they put on are the highlights of our child's year... They came back enthused, confident, proud and talking with excitement about how they are unique."***
>
> *Parent*



Family support: Case study

As the family became more involved, events helped them build stronger community connections. These experiences had a powerful impact on both the parents and their child:



For the young person, meeting others with shared experiences was especially important: ***"The best thing about the events is meeting other children who also have Usher syndrome... we have so many shared experiences."***

Over time, the family gained confidence, knowledge and connection, becoming active in the community and beginning to support others. ***"It feels an awful lot better now that we know we are not alone."***

This family's experience reflects the wider impact of our family support:

- Supporting parents and children to feel part of a community
- Providing trusted information from diagnosis onwards
- Creating opportunities for meaningful peer connection
- Building confidence and understanding over time

Training professionals

Over 750 professionals from across healthcare, education and support services received training from Usher Kids UK in 2025.

Training packages have been developed which enable us to offer training which is tailored for different professional audiences. We have delivered training to clinical teams focused on hearing, vision and genetics, as well as with educational and sensory support teams.

Insight from the lived experiences of our community is incorporated into every training session. This brings the content to life and enables professionals to understand the care and support which makes the biggest difference to families living with Usher syndrome



> ***A really useful session and a lot to take away for us in terms of our services and what support we can offer/advise on for those with progressive vision loss coming into the service.***
>
> *Sensory Support professional, Local Authority*

Section 3: Financial accounts

The following pages contain the charity's full financial accounts and statutory information for the year ending 31 December 2025, prepared in accordance with Charity Commission requirements.

Administrative details

Name: Usher Kids UK

Registered Charity Number: 1200796

Registered Office:
16 Heathfield Avenue
Stockport, Cheshire
SK4 4QJ

Trustees
Chloe Joyner (Chair)
Jon Holloway (Treasurer)
Clare Watson
Kathryn Atkinson
Laura Ross

Independent Examiner:
Focal Business Group
Limited 4a Church Street
Market Harborough
Leicestershire
LE16 7AA

Structure, governance & management

STRUCTURE, GOVERNANCE AND MANAGEMENT

The trustees and directors who served during the year to 31 December 2025 were as follows:

Chloe Joyner

Jonathan Holloway

Clare Watson

Kathryn Atkinson

Laura Ross

The Trustees of Usher Kids UK present financial statements of Usher Kids UK (the charity) for the year ended 31 December 2025. The charity was incorporated on the 24 October 2022. The Trustees confirm the financial statements of the charity comply with the current statutory requirements and the requirements of the charity's governing document.

The company is constituted as a Charitable Incorporated Organisation whose only voting members are its charity trustees.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Reserves

At 31 December 2025, total assets stood at £107,906. Of this, restricted funds totalled £58,261 and unrestricted funds totalled £49,645. Within unrestricted funds, the charity distinguishes between free reserves and designated funds, in line with Charity Commission guidance.

At 31 December 2025, the Charity held £9,645 in free reserves, providing limited flexibility to respond to unforeseen events or short-term funding gaps. A designated fund of £40,000 is held to manage financial risk and support business continuity, equivalent to approximately six months of staffing and core operational costs. These designations ensure financial stability while avoiding the accumulation of surplus funds that are not required for the charity's charitable purposes.

The reserves approach is documented in our Reserves Policy which is reviewed annually.

Public Benefit

The Trustees of the charity confirm they have complied with the duty in Section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission in determining the range of activities undertaken by the charity. The Trustees confirm that in planning the activities of the charity, that such activity is undertaken in the best interest of beneficiary groups and not at the detriment or exclusion of any beneficiaries.

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.

Objectives and activities

OBJECTIVES AND ACTIVITIES

Objectives and aims

The constitutional objective of the charity is to relieve the needs of children and young people (aged 0-25yrs) and their families living with Usher syndrome in the UK, through the provision of support, information, connections and advocacy.

TRUSTEES' AND DIRECTORS' RESPONSIBILITIES

The trustees are required to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and of the surplus or deficit of the charity for that period. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently.

- Make judgments and estimates that are reasonable and prudent.

- State whether the applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements.

- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

On behalf of the trustees.

J Holloway

Signed:

Jonathan Holloway

Treasurer

Independent Examiner's report

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF USHER KIDS UK

I report on the accounts for the year ended 31 December 2025 set out on pages 9 and 10.

Respective responsibilities of trustees and examiner

The trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the Charities Act,

- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and

- to state whether particular matters have come to my attention

Basis of the independent examiners report

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- relevant accounting records were not kept; or

- the accounts do not accord with such records.

I 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.

M. Osborne

Michael Osborne
Focal Business Group Limited
4a Church Street,
Market Harborough,
Leicestershire, LE16 7AA

Statement of Financial Activities

USHER KIDS UK

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR 31 DECEMBER 2025

CHARITY COMMISSION FOR ENGLAND AND WALES

Usher Kids UK	1200796	CC16a

Receipts and payments accounts

For the period from	01/01/2025	To	31/12/2025

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donation Income	22,841	-	-	22,841	-
Grant Income	-	102,123	-	102,123	-
Other Income (Refunds)	832	-	-	832	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	23,673	102,123	-	125,796	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	23,673	102,123	-	125,796	-
A3 Payments					
Charity Activities	1,023	87,778	-	88,801	-
Fundraising Activities	331	-	-	331	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,355	87,778	-	89,132	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	1,355	87,778	-	89,132	-
Net of receipts/(payments)	22,319	14,345	-	36,664	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	27,326	43,916	-	71,242	-
Cash funds this year end	49,645	58,261	-	107,906	-

Statement of Financial Activities

USHER KIDS UK

STATEMENT OF ASSETS AND LIABILITIES
AS AT 31 DECEMBER 2025

Section B Statement of assets and liabilities at the end of the period				
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Natwest current account @ 31/12/2025	49,645	58,261	-
		-	-	-
		-	-	-
	Total cash funds	49,645	58,261	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds	Restricted funds	Endowment funds
	Details	to nearest £	to nearest £	to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Accountancy	Unrestricted	300	30 April 2026
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name		Date of approval

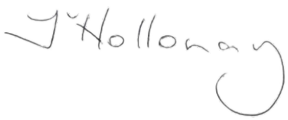
Statement of Assets & Liabilities

USHER KIDS UK

STATEMENT OF ASSETS AND LIABILITIES - CONTINUED
AS AT 31 DECEMBER 2025

The charity trustees must comply with the requirements of the Charities Act 2011 with regard to the keeping of accounting records, to the preparation and scrutiny of statements of account, and to the preparation of annual reports and returns.

The financial statements were approved by the Trustees on 17 June 2026 and were signed on its behalf by:



Jonathan Holloway
Treasurer

Notes to the financial statements

USHER KIDS UK

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 DECEMBER 2025

1. ACCOUNTING POLICIES

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.

Donated services and facilities
Where services are provided to the charity as a donation that would normally be purchased from a supplier, this contribution is included in the financial statements at an estimate based on the value of the contribution to the charity.

2. TRUSTEES' RENUMERATION AND BENEFITS

There were no trustees' renumeration or benefits paid for the year ended 31 December 2025.

3. ULTIMATE CONTROLLING PARTY

The Charity is under the joint control of the trustees.

4. TAXATION

The company is treated as a charity within the meaning of the Income tax and Corporation Taxes Act 1988 and has been afforded exemptions from taxation under section 505 of that act.

5. STATEMENT OF ASSETS AND LIABILITIES

In accordance with the Charitable Incorporation Organisations (General) Regulations 2012, Part 10, Regulation 62, the Trustees provide the following information by way of notes to the statements of assets and liabilities, that in the respect of the following requirements:

a) Particulars of any guarantee given by the CIO, where any potential liability under the guarantee is outstanding at the date of statement, and
b) Particulars of any debt outstanding which is owned by the CIO and which is secured by an express charge on any assets of the CIO

That there are no such guarantees and no such debts outstanding at the date of this statement.

Section 5:
Other important information

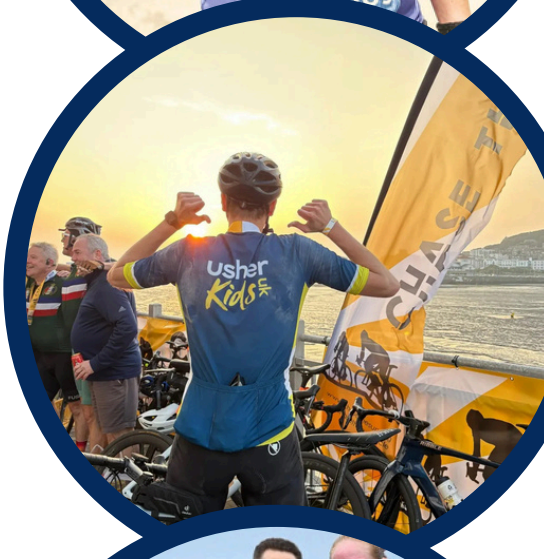
The following pages complete this annual report with information on the supporters who make our work possible and how to connect with and support Usher Kids UK.

Thank you to our supporters

We thank our volunteers (including our trustees) for their dedication, our partners for their collaboration, and our grant providers and donors for making this work possible.

Together we are changing the experiences and outcomes for the next generation living with Usher syndrome.







COMMUNITY FUND

DeafblindUK

POSTCODE LOTTERY

FIGHT FOR SIGHT

ARTEMIS CHARITABLE FOUNDATION

THE POWELL FAMILY FOUNDATION

The Shears Foundation

How to connect with us

usherkidsuk.org

@usherkidsuk

Usher Kids UK

@usherkidsuk





Join our mailing list: info@usherkidsuk.org

Help us change outcomes for the next generations living with Usher syndrome,
via **JustGiving**