

Charity registration number: 1152445

# Wolfram Syndrome UK

Annual Report and Financial Statements

for the Year Ended 28 February 2025

Hodson & Co  
Wiston House  
1 Wiston Avenue  
Worthing  
West Sussex  
BN14 7QL

## Wolfram Syndrome UK

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## **Wolfram Syndrome UK**

### **Reference and Administrative Details**

<b>Chairman</b>	Mr J Isherwood
<b>Trustees</b>	Mr A Nye Prof T Barrett Mr P Lynch Mr J Isherwood Miss A Gardner
<b>Senior Management / Leadership Team</b>	Mrs T Lynch, Chief Executive Dr G Isherwood PhD, Contracts Manager
<b>Charity Registration Number</b>	1152445
<b>Registered Office</b>	The charity is incorporated in England and Wales. 9 Church Way Tarring Worthing West Sussex BN13 1HD
<b>Independent Examiner</b>	Hodson & Co Wiston House 1 Wiston Avenue Worthing West Sussex BN14 7QL

## Wolfram Syndrome UK

### Trustees' Report

The trustees, who are directors for the purposes of company law, present the annual report together with the financial statements and auditors' report of the charitable company for the year ended 28 February 2025.

#### **Objectives and activities**

##### *Objects and aims*

Wolfram Syndrome (WS) is a genetic disorder causing Diabetes Insipidus, Diabetes Mellitus, optic atrophy and deafness. It affects children and adults and there is currently no known cure. There are currently around 143 people diagnosed with WS in the UK. This number is rising and expected to reach 170 due to increased genetic testing and improvements in the diagnosis of Wolfram Related Syndrome. WSUK exists to meet the needs of the WS community – the children, young people and adults affected by WS and their families. Due to the rare and under-researched nature of this illness, diagnosis currently takes 3-6 months and involves several thousand tests. There is only one recognised centre of expertise for children, which is at Birmingham Children's Hospital (BCH); and for adults, at Queen Elizabeth Hospital (QEH) Birmingham; therefore, it is believed that many cases may not be recognised.

WSUK raises funds to help finance further research and through its e-newsletters, website and annual conference increase levels of awareness, knowledge and understanding of this illness. These activities benefit not only those currently affected but also those diagnosed in the future and their families, not least in sustaining an enhanced national focus on finding effective treatments and an eventual cure.

For those currently affected and their families, WSUK maintains a voluntary register and distributes information about its aims, objectives and activities. WSUK provides direct and practical benefit through information, on-going front-line support, advice and guidance including at the WS multi-disciplinary clinics at BCH. Further practical and emotional benefit is provided by WSUK to families living with WS in the form of an annual conference, activities / projects for specific members of the WS community (e.g. WS affected adults) and virtual or in person family / community meetings.

As it is important for the WS community to have opportunities to meet in between the annual conferences, WSUK aims to provide social events that enable members of the WS community build relationships and provide peer support in a safe and welcoming space. This may include regular on-line sessions for small groups, and / or in person events or family days at venues around the country. It is intended that WSUK in person events are organised at little or no cost for families and individuals to help maximise participation. In addition, WSUK will aim to organise "take a break" opportunities for parents and carers at an affordable cost.

For the benefit of current and future WS affected people the level of awareness, debate and research among the public and within the professional community of medical practitioners is raised through a number of dissemination activities organised through WSUK. From the professional forums initially organised at the Birmingham clinics, WSUK will be able to identify potentially valuable research opportunities that it can support through its family network and financially. The WSUK website is also used to further disseminate research results and publications.

All these activities are aimed at benefiting all families registered with WSUK without any further restriction and regardless of their ability to contribute financially. At the discretion of the trustee's, financial support will be provided where poverty is a barrier to benefit. There will be no private benefits to anyone from WSUK other than as a beneficiary of its stated aims and activities.

No detriment or harm will arise from carrying out any of the aims, objectives or activities of WSUK.

## Wolfram Syndrome UK

### Trustees' Report

#### *Public benefit*

The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning future activities.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

#### **Achievements and performance**

##### **WS Community Support**

During 2024/2025, WSUK continued to provide expert support activities and services to the WS community, specifically through the following: -

1. Contract with Birmingham Women's and Children's NHS Foundation Trust (BWC NHSFT) to support the WS clinic services for children and young people.

In October 2024, WSUK successfully completed the second year of its contract with BWC NHSFT to support the WS Multi-Disciplinary Team (MDT) clinic services, part of the NHS England Highly Specialised Service, provided to affected children / young people (YP), and their parent carers and wider family members.

At the end of Y2 (i.e. Oct 2024), the WSUK Family Support Co-ordinator (FSC) was either supporting or was actively engaged with the majority (~80%) of YP and their families. During Y2, the FSC had delivered or was actively delivering a total of 115 support issues (e.g. involving an external agency or service or providing emotional support to parents), which represents an increase of +40% compared with year 1. During Y2, 14 YP and their families received a home visit from the FSC, which was an increase of +130% compared with Y1. The FSC home visits were conducted for a variety of reasons such as the YP was a new referral to the BCH WS service in Y2 or was seen at a virtual WS clinic.

By Oct 2024, the FSC had also successfully supported the four WS MDT clinics at BCH, which were attended by a total of 25 YP, and two virtual clinics for 8 YP (33 YP in total; 3 of whom were new referrals) and their parent carers. For the Oct 2024 WS MDT clinic, the FSC secured the use of Ronald McDonald House (RMH) on the Sunday evening before clinic for YP and families to meet each other and the FSC in a private and welcoming space. Following a positive response from families, the use of RMH has been secured for the 2025 WS MDT clinics.

In late August 2024, WSUK appointed a second part-time FSC to work alongside the first FSC, extending the expert support resources available to this community. Following this appointment, each YP and their family has been allocated a lead FSC to provide on-going support both during and outside clinic, and both FSCs will attend each WS MDT clinics in person from 2025.

Some of WSUK's on-going activities conducted to support or inform the WS community, continue to form part of the contract BWC NHSFT, namely – i) Annual Conference, ii) managing the WSUK database, iii) WSUK website and iv) quarterly E-Newsletters.

## Wolfram Syndrome UK

### Trustees' Report

In September 2024, WSUK held a face-to-face UK Annual Conference at the same venue as 2023 which caters for many of the community's needs. This event provided an opportunity for members of the WS community to connect with each other in person and engage with WS health professionals in a non-clinic setting. A WS panel session was held for the first time in 2024 with 3 WS adults, who discussed their experiences of living with WS, their daily lives and answered questions from the floor. This session was well received by attendees and therefore a young person's panel is being planned for the 2025 annual conference.

Throughout the year, WSUK has continued to regularly update the charity website (<https://wolframsyndrome.co.uk/>) to ensure that it provides the WS community with accurate, current and family-friendly information on WS-related issues, which is medically endorsed. In addition, WSUK has continued to deliver quarterly e-newsletters to all those in the WS community and its supporters who elect to receive regular updates. Each newsletter includes information on a range of topics for example, updates on the latest research, including the TREATWolfram clinical trial. Each newsletter is distributed by email, uploaded on the WSUK website, and shared via WSUK social media. To help ensure the e-newsletter is as accessible as possible, visually impaired (VI) members who use a screen reader receive a text alternative for any included images. In addition, an audio version is made available through the WSUK website and on social media, and a large font printed copy is posted to a small number of members, where specifically requested.

#### 2. Focused support for WS affected adults.

During 2024/2025, the WSUK Adult Support Co-ordinator (ASC) continued to engage with the WS affected adult community to provide on-going, focused support through activities such as: -

i. Attendance at the WS Adult MDT clinics at Queen Elizabeth Hospital (QEH).

During 2024/2025, the ASC attended five WS MDT clinics at QEH (83%) and met a total of 25 WS affected adults and their family members in person to better understand their current situation, any challenges, and on-going support needs. Through attending these clinics in person, the ASC has also extended their relationships with the adult clinic lead and other members of the MDT team.

ii. On-going front-line support

In addition to the WS MDT clinics, during 2024/2025, the ASC developed strong connections with +50% of adults and ~67% of family members. The ASC provided expert support with a range of activities, including, but not limited to: - 15+ emotional wellbeing support calls, adult social care referrals, MDT meetings with external stakeholders, housing issues, clinical and medical queries, and benefit queries.

By Feb 2025, the ASC had conducted 8 home visits to help support WS affected adults and their families in person. The ASC home visits were conducted for a variety of reasons including for example, the symptoms, health status and / or communication needs of the WS affected adult, which meant that a face-to-face discussion was much more valuable for everyone involved compared with a phone call or virtual meeting.

Through all these activities, the ASC continued to build strong and trusted relationships with many WS affected adults and their families; and intends to expand and extend these relationships during 2025/26.

## **Wolfram Syndrome UK**

### **Trustees' Report**

#### **Research**

##### **1. TREATWolfram clinical trial**

A total of 63 children, young people and adults were recruited to the TREATWolfram clinical trial across the UK and at three other international sites. WSUK has previously provided funds to this trial to help support patient visit costs for UK participants. The final trial patients completed their last visits in October 2024. All data was due to be locked by the end of December 2024, but at the WSUK financial year (i.e. 28/02/2025), this had not been achieved due to delays by one of the French sites.

The final WSUK payment to support TREATWolfram was originally deferred following patient recruitment delays due to the COVID pandemic. During 2022/23, the trial lead confirmed that additional funds would not be required for the remainder of the study and in addition, any surplus funds would be returned to WSUK once final payments had been made. As such, both the final payment and any surplus will remain restricted funds and will be allocated to help support future clinical trials conducted in the UK or other research activities.

##### **2. WSUK Scientific Advisory Board**

In October 2024 a second small grant was paid to a research project by KU Leuven University in Belgium, following a recommendation by the WSUK Scientific Advisory Board (SAB) that this would be a valuable project for the charity to support if sufficient funds were available. This project was co-funded by WSUK and The Snow Foundation, USA.

In January 2025, the WSUK SAB met to discuss the research proposals received for the small grant funding of £12,000 for the 2024/25 financial year. A decision was made to award these funds to a research project in Montpellier University, France. The funds will be released in the next WSUK financial year (i.e. 2025/2026) due to the amendments to the paperwork required by the grant recipient.

##### **3 WS International Research Symposium**

In October 2024, WSUK co-hosted the 9th WS International Researchers Symposium in Windsor. 33 global researchers and pharma representatives spent two days discussing their current research projects and clinic trials. The programme was specifically designed to give participants time to hear the presentations, ask questions and talk with other researchers informally between sessions, and has resulted in some new collaborations between global research teams. The symposium ended with all participants collaborating on a plan to create an updated version of Clinical Guidelines for Wolfram Syndrome with a deadline for 1st October 2025, WS Global Awareness Day, for distribution to medical organisations, healthcare professionals and other relevant groups around the world.



## Wolfram Syndrome UK

### Trustees' Report

#### Fundraising

Consistent with previous years, fundraising activities were conducted throughout the year by the WSUK team, the WS community and its supporters. Specific examples include, but are not limited to: -

i. Monthly donations –

Members of the WS community and WSUK supporters continued with their regular monthly donations, which were greatly received and hugely appreciated.

ii. Local fundraising events by WSUK supporters –

Examples include: - a local recruitment company hosted a charity football match and a 6-a-side tournament with 10 teams during the year. WSUK attended each event to support the players, raise the awareness of WS and highlight how their donations help this community.

iii. Community donations –

Throughout the year, members of the WS community completed fundraising activities or made donations to help support the charity. Examples include: - Half marathons, an 80-mile ride for an 80th birthday, a Christmas Hamper Draw.

iv. Annual Golf Day event –

The 11th WSUK Annual Golf Day was held in July 2024. The participating teams, many of whom have been involved in previous events, again raised a substantial amount of funds for the charity.

v. Sale of UK branded items –

Similar with previous years, items such as Christmas cards, water bottles and pens were sold through both the WSUK website and social media accounts, conference and at charity fundraising events.

vi. Christmas Hamper Raffle –

In December 2024, a local boutique restaurant held a hamper raffle of 100 tickets to raise £500.

WSUK thanks everyone in the WS community and its supporters for their continued support in helping the charity to raise funds to deliver its important work.



WS Global Awareness Day 1st October

The fourth WS Global Awareness Day took place on October 1st 2024. WS related information was distributed to global organisations to help raise their awareness of the condition. WSUK intends to hold the fifth WS Global Awareness Day on 1st October 2025 when it is intended that the new Clinical Guidelines for Wolfram Syndrome will be available for dissemination to medical practitioners globally.





## **Wolfram Syndrome UK**

### **Trustees' Report**

#### **Financial review**

Total incoming resources for the year were £121,228 (2024: £136,399) with expenditure of £139,723 (2023: £113,865). Overall, there was a deficit for the year of £18,495 (2024: surplus £22,534). Unrestricted funds at the year-end were £28,508 (2023: £37,569) and the restricted funds were £84,023 (2023: £93,457). Total funds for the year were £112,531 (2023: £131,026).

#### **Policy on reserves**

The trustees have examined the charity's requirements for reserves in light of the main risks to the organisation. The trustees consider that the present level of funding will be adequate to support the continuation of the charity and for it to fulfil its obligations.

#### **Investment policy and objectives**

The objects of the company authorises it to invest and deal with moneys not immediately required for its purposes in and upon such investments securities and property as may be thought fit.

#### **Going concern**

The charity has reviewed its financial performance and general reserves position. The charity has adequate financial resources and is able to manage its business risks. The charity's planning process has taken into consideration the current economic climate and its potential impact on the various sources of income and planned expenditure.

Taking into account all factors the charity has reasonable expectation that it has adequate resources to continue in operational existence for the foreseeable future and believe that there are no material uncertainties that call into the charity's ability to continue in operation.

Accordingly, the accounts have been prepared on the basis that the charity is a going concern.

#### **Structure, governance and management**

##### ***Nature of governing document***

Wolfram Syndrome UK is a Charitable Incorporated Organisation registered on 17 June 2013 with the Charity Commission of England and Wales (no. 1152445). The charity's working name is WSUK.

##### **Trustees**

Mr A Nye

Prof T Barrett

Mr P Lynch

Mr J Isherwood

Miss A Gardner

Mr N Mistry (resigned 4 June 2024)

##### ***Recruitment and appointment of trustees***

The Board has the power to appoint additional trustees as it considers fit to do so.

None of the trustees has any beneficial interest in the charity.

## Wolfram Syndrome UK

### Trustees' Report

#### *Induction and training of trustees*

Potential trustees are selected on the basis of their personal qualities and the complex issues involved. A speciality linking to charity needs is also sought. New trustees are made familiar with the charity vision, operation and goals by dialogue with existing personnel and provision of minutes and other literature pertaining to charity activity.

All trustees are already familiar with the practical work of the charity. New trustees are encouraged to attend all management committee meetings. Short training sessions (if required) to familiarise new trustees with the charity and the context within which it operates are provided.

#### *Organisational structure*

The charity is organised so that the trustees meet regularly to manage its affairs. The trustees meet at least quarterly with additional meetings as required. The charity is overseen by the trustees, supported by volunteers. The organisation operates in the UK from premises in Church Road, Worthing.

Key strategic and administrative decisions are made by agreement of the trustees, and delegated as appropriate. Day to day management of the charity is delegated to the Chief Executive, Mrs Tracy Lynch.

#### *Financial instruments*

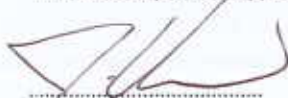
#### *Objectives and policies*

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

#### *Disclosure of information to auditor*

Each trustee has taken steps that they ought to have taken as a trustee in order to make themselves aware of any relevant audit information and to establish that the charity's auditor is aware of that information. The trustees confirm that there is no relevant information that they know of and of which they know the auditor is unaware.

The annual report was approved by the trustees of the charity on 28/11/25 and signed on its behalf by:



Mr J Isherwood  
Chairman and trustee

## Wolfram Syndrome UK

### Statement of Trustees' Responsibilities

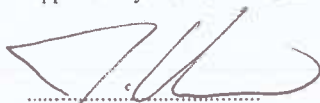
The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Charity SORP requires the trustees to prepare financial statements for each financial year. The trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the charity and of the incoming resources and application of resources, including its income and expenditure, of the charity for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- 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 accounting records that disclose with reasonable accuracy at any time the financial position of the charity. 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.

Approved by the trustees of the charity on 28/11/25 and signed on its behalf by:



Mr. J. Isherwood  
Chairman and trustee

## Wolfram Syndrome UK

### Independent Examiner's Report to the trustees of Wolfram Syndrome UK

I report to the charity trustees on my examination of the accounts of the Charity for the year ended 28 February 2025.

#### Responsibilities and basis of report

As the charity's trustees you 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 independent examiner's statement

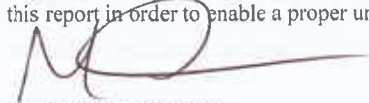
My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures 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:

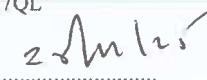
- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and 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 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.



Matthew Hodson FCA  
Independent Examiner

Wiston House  
1 Wiston Avenue  
Worthing  
West Sussex  
BN14 7QL



Date:.....

## Wolfram Syndrome UK

### Statement of Financial Activities for the Year Ended 28 February 2025 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2025 £
<b>Income and Endowments from:</b>				
Donations and legacies	3	9,091	644	9,735
Other trading activities	4	38,530	72,307	110,837
Investment income	5	-	656	656
Total Income		<u>47,621</u>	<u>73,607</u>	<u>121,228</u>
<b>Expenditure on:</b>				
Raising funds	6	(29,549)	-	(29,549)
Charitable activities	7	(27,133)	(83,041)	(110,174)
Total Expenditure		<u>(56,682)</u>	<u>(83,041)</u>	<u>(139,723)</u>
Net expenditure		<u>(9,061)</u>	<u>(9,434)</u>	<u>(18,495)</u>
Net movement in funds		(9,061)	(9,434)	(18,495)
<b>Reconciliation of funds</b>				
Total funds brought forward		<u>37,569</u>	<u>93,457</u>	<u>131,026</u>
Total funds carried forward	18	<u>28,508</u>	<u>84,023</u>	<u>112,531</u>

The notes on pages 14 to 26 form an integral part of these financial statements.

## Wolfram Syndrome UK

### Statement of Financial Activities for the Year Ended 28 February 2025 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2024 £
<b>Income and Endowments from:</b>				
Donations and legacies	3	15,108	24,392	39,500
Other trading activities	4	45,737	50,662	96,399
Investment income	5	500	-	500
Total Income		<u>61,345</u>	<u>75,054</u>	<u>136,399</u>
<b>Expenditure on:</b>				
Raising funds	6	(48,478)	-	(48,478)
Charitable activities	7	(4,737)	(60,650)	(65,387)
Total Expenditure		<u>(53,215)</u>	<u>(60,650)</u>	<u>(113,865)</u>
Net income		8,130	14,404	22,534
Transfers between funds		<u>(2,500)</u>	<u>2,500</u>	<u>-</u>
Net movement in funds		5,630	16,904	22,534
<b>Reconciliation of funds</b>				
Total funds brought forward		<u>31,939</u>	<u>76,553</u>	<u>108,492</u>
Total funds carried forward	18	<u>37,569</u>	<u>93,457</u>	<u>131,026</u>

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2024 is shown in note 18.

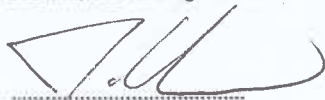


# Wolfram Syndrome UK

## Balance Sheet as at 28 February 2025

	Note	2025 £	2024 £
<b>Fixed assets</b>			
Tangible assets	14	231	241
<b>Current assets</b>			
Stocks	15	967	425
Debtors	16	267	1,110
Cash at bank and in hand		<u>114,891</u>	<u>131,816</u>
		116,125	133,351
<b>Creditors: Amounts falling due within one year</b>	17	<u>(3,825)</u>	<u>(2,566)</u>
<b>Net current assets</b>		<u>112,300</u>	<u>130,785</u>
<b>Net assets</b>		<u>112,531</u>	<u>131,026</u>
<b>Funds of the charity:</b>			
<b>Restricted income funds</b>			
Restricted funds	18	84,023	93,457
<b>Unrestricted income funds</b>			
Unrestricted funds		<u>28,508</u>	<u>37,569</u>
<b>Total funds</b>	19	<u>112,531</u>	<u>131,026</u>

The financial statements on pages 11 to 26 were approved by the trustees, and authorised for issue on 28/11/25 and signed on their behalf by:



Mr V. Isherwood  
Chairman and Trustee

## **Wolfram Syndrome UK**

### **Notes to the Financial Statements for the Year Ended 28 February 2025**

#### **1 Charity status**

The charity is a Charitable Incorporated Organisation (CIO) and consequently does not have share capital.

The address of its registered office is:

9 Church Way

Tarring

Worthing

West Sussex

BN13 1HD

#### **2 Accounting policies**

##### **Summary of significant accounting policies and key accounting estimates**

The principal accounting policies applied in the preparation of these financial statements are set out below.

These policies have been consistently applied to all the years presented, unless otherwise stated.

##### **Statement of compliance**

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)) (issued in October 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

##### **Basis of preparation**

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

The financial statements are prepared in sterling, which is the functional currency of the entity.

##### **Going concern**

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern nor any significant areas of uncertainty that affect the carrying value of assets held by the charity.

##### **Income and endowments**

All income is recognised once the charity has entitlement to the income, it is probable that the income will be received and the amount of the income receivable can be measured reliably.

##### **Donations and legacies**

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance by the charity before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that these conditions will be fulfilled in the reporting period.

## **Wolfram Syndrome UK**

### **Notes to the Financial Statements for the Year Ended 28 February 2025**

#### ***Grants receivable***

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

#### ***Investment income***

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

#### ***Expenditure***

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis which is reasonable, justifiable and consistent.

#### ***Raising funds***

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

#### ***Charitable activities***

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

#### ***Support costs***

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

#### ***Governance costs***

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees meetings and reimbursed expenses.

#### ***Taxation***

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

#### ***Tangible fixed assets***

Individual fixed assets are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

#### ***Depreciation and amortisation***

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

Asset class	Depreciation method and rate
Plant and machinery	over 4 years
Office equipment	between 2 and 5 years

#### Impairment of fixed assets

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date.

#### Research and development

Research and development expenditure is written off as incurred.

#### Stock

Stock is valued at the lower of cost and estimated selling price less costs to complete and sell, after due regard for obsolete and slow moving stocks. Cost is determined using the first-in, first-out (FIFO).

#### Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

#### Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the charity does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

#### Fund structure

Unrestricted income funds are general funds that are available for use at the trustees discretion in furtherance of the objectives of the charity.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

#### Financial instruments

##### Classification

The charity only has financial assets and liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

#### 3 Income from donations and legacies

	Unrestricted funds General £	Restricted funds £	Total 2025 £	Total 2024 £
Donations and legacies;				
Donations from individuals	4,659	644	5,303	25,417
Grants, including capital grants;				
Grants from other charities	3,009	-	3,009	10,224
Regular giving and capital donations	<u>1,423</u>	<u>-</u>	<u>1,423</u>	<u>3,859</u>
	<u>9,091</u>	<u>644</u>	<u>9,735</u>	<u>39,500</u>

#### 4 Income from other trading activities

	Unrestricted funds General £	Restricted funds £	Total funds £	Total 2024 £
Trading income;				
Sales of goods and services	375	-	375	279
Other trading income	-	72,307	72,307	50,662
Events income;				
Other events income	<u>38,155</u>	<u>-</u>	<u>38,155</u>	<u>45,458</u>
	<u>38,530</u>	<u>72,307</u>	<u>110,837</u>	<u>96,399</u>

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

#### 5 Investment income

	Restricted funds £	Total 2025 £	Total 2024 £
Interest receivable and similar income; Interest receivable on bank deposits	656	656	500

#### 6 Expenditure on raising funds

##### a) Costs of generating donations and legacies

	Unrestricted funds General £	Total 2025 £	Total 2024 £
Note			
Marketing and publicity	-	-	3,168
Allocated support costs	7,557	7,557	8,007
	7,557	7,557	11,175

##### b) Costs of trading activities

	Unrestricted funds General £	Total 2025 £	Total 2024 £
Note			
Costs of goods sold	383	383	289
Depreciation, amortisation and other similar costs	140	140	181
Other direct costs of activities for generating funds	21,469	21,469	36,833
	21,992	21,992	37,303



## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

#### 7 Expenditure on charitable activities

	Note	Unrestricted funds General £	Restricted funds £	Total 2025 £	Total 2024 £
Wolfram Syndrome Research		233	16,895	17,128	-
Support for WS community		22,147	60,155	82,302	60,951
Conference costs		-	5,991	5,991	(133)
Governance costs	8	4,753	-	4,753	4,569
		<u>27,133</u>	<u>83,041</u>	<u>110,174</u>	<u>65,387</u>

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

#### 8 Analysis of governance and support costs

##### Raising funds expenditure

##### Support costs allocated to raising funds

	Administration costs £	Total 2025 £	Total 2024 £
Costs of generating donations and legacies	7,557	7,557	8,007

##### Governance costs

	Unrestricted funds General £	Total 2025 £	Total 2024 £
Independent examiner fees			
Examination of the financial statements	1,428	1,428	1,344
Professional fees	13	13	13
Other governance costs	3,312	3,312	3,212
	4,753	4,753	4,569

#### 9 Net incoming/outgoing resources

Net (outgoing)/incoming resources for the year include:

	2025 £	2024 £
Depreciation of fixed assets	140	181

#### 10 Trustees remuneration and expenses

During the year the charity made the following transactions with trustees:

##### Mr P Lynch

£1,580 (2024: £Nil) of expenses were reimbursed to Mr P Lynch during the year.

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

#### 11 Staff costs

The aggregate payroll costs were as follows:

	2025 £	2024 £
<b>Staff costs during the year were:</b>		
Wages and salaries	78,217	66,785
Pension costs	<u>2,347</u>	<u>2,004</u>
	<u>80,564</u>	<u>68,789</u>

The monthly average number of persons (including senior management / leadership team) employed by the charity during the year expressed as full time equivalents was as follows:

	2025 No	2024 No
Full time employees	<u>4</u>	<u>4</u>

Contributions to the employee pension schemes for the year totalled £2,347 (2024 - £2,004).

No employee received emoluments of more than £60,000 during the year.

#### 12 Independent examiner's remuneration

	2025 £	2024 £
<b>Other fees to examiners</b>		
The examining of the accounts of the charity	<u>1,428</u>	<u>1,344</u>

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

#### 13 Taxation

The charity is a registered charity and is therefore exempt from taxation.

#### 14 Tangible fixed assets

	Furniture and equipment £	Total £
<b>Cost</b>		
At 1 March 2024	4,732	4,732
Additions	130	130
At 28 February 2025	<u>4,862</u>	<u>4,862</u>
<b>Depreciation</b>		
At 1 March 2024	4,491	4,491
Charge for the year	140	140
At 28 February 2025	<u>4,631</u>	<u>4,631</u>
<b>Net book value</b>		
At 28 February 2025	<u>231</u>	<u>231</u>
At 29 February 2024	<u>241</u>	<u>241</u>

#### 15 Stock

	2025 £	2024 £
Stocks	<u>967</u>	<u>425</u>

#### 16 Debtors

	2025 £	2024 £
Trade debtors	-	866
Prepayments	<u>267</u>	<u>244</u>
	<u>267</u>	<u>1,110</u>

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

#### 17 Creditors: amounts falling due within one year

	2025 £	2024 £
Trade creditors	1,620	41
Other taxation and social security	546	110
Accruals	1,659	2,415
	<u>3,825</u>	<u>2,566</u>

#### 18 Funds

	Balance at 1 March 2024 £	Incoming resources £	Resources expended £	Balance at 28 February 2025 £
<b>Unrestricted funds</b>				
<i>General</i>				
General Funds	32,569	47,622	(56,683)	23,508
<i>Designated</i>				
Research Fund	5,000	-	-	5,000
<b>Total unrestricted funds</b>	<u>37,569</u>	<u>47,622</u>	<u>(56,683)</u>	<u>28,508</u>
<b>Restricted funds</b>				
Wolfram Syndrome Conference	6,006	-	(5,991)	15
Research Fund	34,488	1,300	(16,894)	18,894
BCII NIIS Contract	42,869	72,307	(60,156)	55,020
TREATWolfram	10,094	-	-	10,094
<b>Total restricted funds</b>	<u>93,457</u>	<u>73,607</u>	<u>(83,041)</u>	<u>84,023</u>
<b>Total funds</b>	<u>131,026</u>	<u>121,229</u>	<u>(139,724)</u>	<u>112,531</u>

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

	Balance at 1 March 2023 £	Incoming resources £	Resources expended £	Transfers £	Balance at 29 February 2024 £
<b>Unrestricted funds</b>					
<i>General</i>					
General Funds	26,939	61,345	(53,215)	(2,500)	32,569
<i>Designated</i>					
Research Fund	5,000	-	-	-	5,000
<b>Total unrestricted funds</b>	<b>31,939</b>	<b>61,345</b>	<b>(53,215)</b>	<b>(2,500)</b>	<b>37,569</b>
<b>Restricted</b>					
Wolfram Syndrome Conference	5,890	-	116	-	6,006
Research Fund	20,491	16,215	(2,218)	-	34,488
Breaking Down Barriers	108	-	(108)	-	-
The National Lottery Community Fund - EWB	3,584	-	(3,584)	-	-
Albert Hunt Trust	496	-	(496)	-	-
BCH NHS Contract	33,672	50,662	(41,465)	-	42,869
International Symposium	2,219	8,177	(12,896)	2,500	-
TREATWolfram	10,094	-	-	-	10,094
<b>Total restricted funds</b>	<b>76,554</b>	<b>75,054</b>	<b>(60,651)</b>	<b>2,500</b>	<b>93,457</b>
<b>Total funds</b>	<b>108,493</b>	<b>136,399</b>	<b>(113,866)</b>	<b>-</b>	<b>131,026</b>



## **Wolfram Syndrome UK**

### **Notes to the Financial Statements for the Year Ended 28 February 2025**

The specific purposes for which the funds are to be applied are as follows:

Wolfram Syndrome Conference

Income and costs towards the annual conferences.

Research Fund - Funds raised, donated or designated by WSUK to assist in research of the syndrome.

Breaking Down Barriers

BDB Grant from Sylvia Adams Trust for BAME families project (year 1).

BDB Year 2: A second BDB grant from Sylvia Adams Trust for a project with the WS community across different cultures.

The National Lottery Community Fund (TNLCF) – Awards For All: Carers Wellbeing Pilot Project for WS carers.

The National Lottery Community Fund (TNLCF) – Awards For All: Emotional Wellbeing Project for WS affected adults.

Albert Hunt Trust for support of WS affected adults.

BCH NHS Contract - Provision of WS related support services to Birmingham Children's Hospital.

International Symposium - Funds received towards the cost of holding an international researchers symposium.

TREATWolfram - Funds raised, donated or designated by WSUK to assist families/individuals in covering any travel/accommodation costs that are incurred by them for taking part in the 3 year TREATWolfram clinical trial which started recruitment in January 2019, with regular visits to Birmingham Children's Hospital & Queen Elizabeth Hospital Birmingham.

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2025

#### 19 Analysis of net assets between funds

	Unrestricted funds General £	Restricted funds £	Total funds at 28 February 2025 £
Tangible fixed assets	231	-	231
Current assets	32,102	84,023	116,125
Current liabilities	(3,825)	-	(3,825)
Total net assets	28,508	84,023	112,531

	Unrestricted funds General £	Restricted funds £	Total funds at 29 February 2024 £
Tangible fixed assets	241	-	241
Current assets	39,893	93,458	133,351
Current liabilities	(2,566)	-	(2,566)
Total net assets	37,568	93,458	131,026

#### 20 Analysis of net funds

	At 1 March 2024 £	At 28 February 2025 £
Cash at bank and in hand	131,816	131,816
	131,816	131,816

#### 21 Related party transactions

During the year the charity made the following related party transactions:

##### Tracy Lynch

(Related party of Trustee Paul Lynch)

Gross wages - £18,404 (2024: £17,353). At the balance sheet date the amount due to/from Tracy Lynch was £Nil (2024 - £Nil).

##### Gina Isherwood

(Related party of Trustee John Isherwood)

Gross wages - £21,499 (2024: £20,134). At the balance sheet date the amount due to/from Gina Isherwood was £Nil (2024 - £Nil).