

# Wolfram Syndrome UK

Annual Report and Financial Statements

for the Year Ended 28 February 2023

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 Mr N Mistry
<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 of the charitable company for the year ended 28 February 2023.

### 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 110 people diagnosed with WS in the UK. This number is rising and expected to reach 150 due to increased genetic testing and improvements in the diagnosis of partial Wolfram. 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; and for adults, at Queen Elizabeth Hospital 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. 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 clinic, 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 of these activities are aimed at benefiting all of the 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.

#### *Public benefit*

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



# Wolfram Syndrome UK

## Trustees' Report

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 2022/2023, WSUK significantly extended the support activities and services that the charity provides 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 2022, WSUK secured a contract with BWC NHSFT to support the Multi-Disciplinary Team (MDT) clinic services, part of the NHS England Highly Specialised Service, provided to WS affected children and young people, and their parent carers and wider family members. The specific aims of the contract are to: -

- i. encourage / help families attend WS MDT clinics and gain the most value from their interactions with expert health professionals.
- ii. provide accurate, current, and family-friendly information on all aspects relating to WS.
- iii. provide on-going support and advocacy services to families – including liaising with schools, colleges, and signposting to other external support organisations.
- iv. deliver independent, objective evidence to BCH and wider NHS teams on the level of service provided to families, with recommendations on how the service can continue to be enhanced and developed in the future.

To support the new contract, in August 2022, WSUK appointed two new part-time employees: -

- i. Family Support Co-ordinator (FSC) to deliver expert support services to families both during and outside clinic.
- ii. Contracts Manager to assume overall responsibility for the contract and the charity's associated obligations, and to line manage the Adult and Family Support Co-ordinators.

In January 2023, the Family Support Co-ordinator successfully supported the first MDT WS clinic within the contract, which was attended by 6 children / young people (2 of whom were newly diagnosed) and 9 parent carers. One important metric for the BWC NHSFT team and NHS stakeholders is the number of families who do not attend clinic as expected (i.e., "Did Not Attends" (DNAs)) and aim for the service to achieve the minimal number of DNAs as possible. As all 6 families attended at the WS MDT January clinic as expected, the number of DNAs was zero - a positive achievement. During clinic, the FSC collected feedback directly from those who attended about their experiences, which was consolidated and summarised in a Clinic report and shared with WS expert health professionals in February 2023, prior to the team's post clinic meeting.

Some of WSUK's on-going activities conducted to support or inform the WS community, now also form part of the new 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 and October 2022, WSUK held both a virtual annual conference for the global WS community and a face-to-face UK Annual Conference, the first in person event since 2019 (i.e., since the COVID pandemic. Appropriate precautions were taken to ensure everyone who attended felt safe). As anticipated, both events were well attended. The UK Conference provided a much welcome opportunity for members of the WS community to reconnect with each other in person and engage with WS health professionals in a non-clinic setting. Presentations from both events were recorded and uploaded onto the WSUK website, to enable those who were either unable to attend or part of the ex-UK global community to hear the latest updates from WSUK, researchers and representatives from other relevant organisations. Plans are well underway for the conference in 2023, and a new venue has been secured for the face-face event in a more central location. From 2024, to enable the WS community to receive twice yearly presentation updates from WS experts, the virtual annual conference event will be scheduled in the spring of each year, followed by the UK Conference in the autumn.

Throughout the year, WSUK has continued to regularly update the charity website 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 social media accounts, and a large font printed copy is posted to a small number of members, where specifically requested.

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

A new Adult Support Co-ordinator (ASC) was appointed in September 2023 who has been able to engage with the WS affected adult community and provide enhanced support through activities such as: -

#### i. Attendance at the WS Adult MDT clinics at Queen Elizabeth Hospital.

The ASC has been able to meet WS affected adults and their family members in person and better understand their situation, current challenges and support needs.

#### ii. The Emotional Wellbeing project for WS affected adults.

This project was designed to help empower WS affected adults to improve their emotional wellbeing and funded through a grant received from the National Lottery Community Fund in January 2022. WSUK has developed a project specific webpage to provide the WS community with information on different aspects of wellbeing from a range of recognised sources.

Since September 2022, following a temporary pause due to a change of staff, the new ASC has held regular 1:1 monthly personalised support sessions with WS affected adults to provide a safe space to talk and share their difficulties, develop strong and trusted relationships, and help improve their emotional wellbeing. Through building these relationships, the ASC has started to bring together and help facilitate small groups of WS affected adults with similar backgrounds, experiences and / or struggles, to meet on a regular basis to share their perspectives and offer / receive peer support in a welcoming space.





# Wolfram Syndrome UK

## Trustees' Report

### 3. Completion of Y2 BDB project

In July 2022, WSUK formally completed its second Breaking Down Barriers (BDB) project, which was part of the initiative, run by Alstrom Syndrome UK and funded by the Sylvia Adams Charitable Trust. These BDB projects were aimed to help WSUK develop and extend its relationships with the WS community from minority ethnic backgrounds and to develop more inclusive activities and services. In year 2, members of the WS community from a range of backgrounds shared their experiences on different aspects of living with WS (e.g., living independently, leisure activities and parents' views of WS), which were recorded by WSUK. Short video clips were produced from each recording and made available on the BDB-specific hub on the WSUK website, which was developed to provide a central location for project-related materials. The video clips provide insights on how WS can affect daily life and highlight how despite some challenges, the community remains positive and seeks to remain as active as possible. As such, they represent an important resource for WSUK's current and future members, its supporters and stakeholders.



### Research

#### 1. TREATWolfram clinical trial

A total of 63 children, young people and adults have been 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 first young people who were recruited at Birmingham Children's Hospital, have now completed their last patient visits, while the final patients recruited will complete their last visits in November 2024.

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

During 2022/23, WSUK established a Scientific Advisory Board of scientific / research experts to evaluate and advise where WSUK should direct charity funding for research activities. Board policy and guidance documents have been developed and shared with members, who will meet to discuss the first research opportunities during 2023/24.

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## 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 2 charity football matches during the year. WSUK attended each event to support the players, raise the awareness of WS and highlight how their donations help this community. Following two successful events, the company has confirmed its continued fundraising support during 2023/24.

iii. Community donations –

Throughout the year members of the WS community completed fundraising activities or made donations to help support the charity.

iv. Annual Golf Day event –

The 9th WSUK Annual Golf Day was held in July 2023. The participating teams, many of whom have been involved in previous events, raised a record amount for the charity and greater than pre-pandemic levels.

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, and at charity fundraising events.

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 second WS Global Awareness Day took place on October 1st 2022, which was the same date as the 2022 WSUK Annual Conference. WS related information was distributed to global organisations that were not contacted in the first year's event, to help raise their awareness of the condition. WSUK intends to hold the third WS Global Awareness Day on 1st October 2023, which will again coincide with the timing of the 2023 WSUK Conference (29th / 30th September 2023).



# Wolfram Syndrome UK

## Trustees' Report



### **Financial review**

Total incoming resources for the year were £108,116 (2022: £43,157) with expenditure of £64,912 (2022: £48,197). Overall, there was a surplus for the year of £43,204 (2022: deficit £5,040). Unrestricted funds at the year-end were £37,826 (2022: £17,679) and the restricted funds were £70,665 (2022: £47,608). Total funds for the year were £108,491 (2022: £65,287).

### **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.

#### ***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.

The annual report was approved by the trustees of the charity on 13/11/2023 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 13/11/2023 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 2023.

### 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: 13/4/2023

## Wolfram Syndrome UK

### Statement of Financial Activities for the Year Ended 28 February 2023 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2023 £
<b>Income and Endowments from:</b>				
Donations and legacies	3	28,658	4,819	33,477
Other trading activities	4	20,895	53,725	74,620
Investment income	5	19	-	19
Total Income		<u>49,572</u>	<u>58,544</u>	<u>108,116</u>
<b>Expenditure on:</b>				
Raising funds	6	(25,335)	(17,308)	(42,643)
Charitable activities	7	<u>(9,979)</u>	<u>(12,289)</u>	<u>(22,268)</u>
Total Expenditure		<u>(35,314)</u>	<u>(29,597)</u>	<u>(64,911)</u>
Net income		<u>14,258</u>	<u>28,947</u>	<u>43,205</u>
Net movement in funds		14,258	28,947	43,205
<b>Reconciliation of funds</b>				
Total funds brought forward		<u>17,679</u>	<u>47,608</u>	<u>65,287</u>
Total funds carried forward	18	<u><u>31,937</u></u>	<u><u>76,555</u></u>	<u><u>108,492</u></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 2023 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2022 £
<b>Income and Endowments from:</b>				
Donations and legacies	3	3,826	16,671	20,497
Other trading activities	4	22,656	-	22,656
Investment income	5	4	-	4
Total Income		<u>26,486</u>	<u>16,671</u>	<u>43,157</u>
<b>Expenditure on:</b>				
Raising funds	6	(21,263)	-	(21,263)
Charitable activities	7	(15,025)	(11,909)	(26,934)
Total Expenditure		<u>(36,288)</u>	<u>(11,909)</u>	<u>(48,197)</u>
Net (expenditure)/income		(9,802)	4,762	(5,040)
Transfers between funds		<u>69</u>	<u>(69)</u>	<u>-</u>
Net movement in funds		(9,733)	4,693	(5,040)
<b>Reconciliation of funds</b>				
Total funds brought forward		<u>27,412</u>	<u>42,915</u>	<u>70,327</u>
Total funds carried forward	18	<u>17,679</u>	<u>47,608</u>	<u>65,287</u>

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

The funds breakdown for 2022 is shown in note 18.

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




# Wolfram Syndrome UK

## Balance Sheet as at 28 February 2023

	Note	2023 £	2022 £
<b>Fixed assets</b>			
Tangible assets	14	147	509
<b>Current assets</b>			
Stocks	15	837	932
Debtors	16	671	2,040
Cash at bank and in hand		108,066	64,907
		109,574	67,879
<b>Creditors: Amounts falling due within one year</b>	17	(1,229)	(3,101)
<b>Net current assets</b>		108,345	64,778
<b>Net assets</b>		108,492	65,287
<b>Funds of the charity:</b>			
<b>Restricted income funds</b>			
Restricted funds	18	76,553	47,608
<b>Unrestricted income funds</b>			
Unrestricted funds		31,939	17,679
<b>Total funds</b>	19	108,492	65,287

The financial statements on pages 11 to 26 were approved by the trustees, and authorised for issue on 13/11/2023 and signed on their behalf by:

  
 Mr. J. Isherwood  
 Chairman and Trustee

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

# **Wolfram Syndrome UK**

## **Notes to the Financial Statements for the Year Ended 28 February 2023**

### **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 2023**

### ***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 2023

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 2023

### 3 Income from donations and legacies

	Unrestricted funds General £	Restricted funds £	Total 2023 £	Total 2022 £
Donations and legacies;				
Donations from individuals	27,730	-	27,730	3,850
Grants, including capital grants;				
Grants from other charities	427	4,819	5,246	15,995
Regular giving and capital donations	501	-	501	652
	<u>28,658</u>	<u>4,819</u>	<u>33,477</u>	<u>20,497</u>

### 4 Income from other trading activities

	Unrestricted funds General £	Restricted funds £	Total funds £	Total 2022 £
Trading income;				
Sales of goods and services	330	-	330	331
Other trading income	-	48,400	48,400	-
Events income;				
Other events income	20,565	5,325	25,890	22,325
	<u>20,895</u>	<u>53,725</u>	<u>74,620</u>	<u>22,656</u>

# Wolfram Syndrome UK

## Notes to the Financial Statements for the Year Ended 28 February 2023

### 5 Investment income

	Unrestricted funds General £	Total 2023 £	Total 2022 £
Interest receivable and similar income;			
Interest receivable on bank deposits	19	19	4

### 6 Expenditure on raising funds

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

	Note	Unrestricted funds General £	Total 2023 £	Total 2022 £
Marketing and publicity		166	166	-
Allocated support costs	8	1,590	1,590	1,484
		1,756	1,756	1,484

#### b) Costs of trading activities

	Note	Unrestricted funds General £	Restricted funds £	Total 2023 £	Total 2022 £
Costs of goods sold	2,346		-	2,346	1,786
Depreciation, amortisation and other similar costs	361		-	361	406
Other direct costs of activities for generating funds		20,872	17,308	38,180	17,587
		23,579	17,308	40,887	19,779



# Wolfram Syndrome UK

## Notes to the Financial Statements for the Year Ended 28 February 2023

### 7 Expenditure on charitable activities

		Unrestricted funds		Restricted funds	Total
	Note	Designated	General	funds	2023
		£	£	£	£
Support for WS community		43	(77)	5,145	5,111
Conference costs		-	-	5,475	5,475
Allocated support costs	8	-	-	531	531
Governance costs	8	-	10,013	1,138	11,151
		<u>43</u>	<u>9,936</u>	<u>12,289</u>	<u>22,268</u>
					Total
				Note	2022
					£
Support for WS community					11,482
Conference costs					(1)
Allocated support costs				8	375
Governance costs				8	15,078
					<u>26,934</u>

# **Wolfram Syndrome UK**

## **Notes to the Financial Statements for the Year Ended 28 February 2023**

### **8 Analysis of governance and support costs**

#### **Raising funds expenditure**

#### **Support costs allocated to raising funds**

	Administration costs £	Total 2023 £	Total 2022 £
Costs of generating donations and legacies	1,590	1,590	1,484

#### **Governance costs**

	Unrestricted funds General £	Restricted funds £	Total 2023 £	Total 2022 £
Independent examiner fees				
Examination of the financial statements	1,452	-	1,452	1,200
Professional fees	5,319	1,138	6,457	11,646
Other governance costs	3,242	-	3,242	2,232
	10,013	1,138	11,151	15,078

### **9 Net incoming/outgoing resources**

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

	2023 £	2022 £
Depreciation of fixed assets	361	406

### **10 Trustees remuneration and expenses**

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

#### **Mr P Lynch**

£1,131 (2022: £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 2023

#### 11 Staff costs

The aggregate payroll costs were as follows:

	2023 £	2022 £
<b>Staff costs during the year were:</b>		
Wages and salaries	37,561	19,329
Pension costs	<u>1,070</u>	<u>440</u>
	<u>38,631</u>	<u>19,769</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:

	2023 No	2022 No
Full time employees	<u>3</u>	<u>1</u>

Contributions to the employee pension schemes for the year totalled £1,070 (2022 - £440).

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

#### 12 Independent examiner's remuneration

	2023 £	2022 £
<b>Other fees to examiners</b>		
The examining of the accounts of the charity	<u>1,452</u>	<u>1,200</u>



# Wolfram Syndrome UK

## Notes to the Financial Statements for the Year Ended 28 February 2023

### 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 2022	4,457	4,457
At 28 February 2023	4,457	4,457
<b>Depreciation</b>		
At 1 March 2022	3,948	3,948
Charge for the year	362	362
At 28 February 2023	4,310	4,310
<b>Net book value</b>		
At 28 February 2023	147	147
At 28 February 2022	509	509

### 15 Stock

	2023 £	2022 £
Stocks	837	932

### 16 Debtors

	2023 £	2022 £
Trade debtors	427	-
Prepayments	244	308
Other debtors	-	1,732
	671	2,040

# Wolfram Syndrome UK

## Notes to the Financial Statements for the Year Ended 28 February 2023

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

	2023 £	2022 £
Trade creditors	59	1,759
Other taxation and social security	(222)	106
Accruals	1,392	1,236
	<u>1,229</u>	<u>3,101</u>

### 18 Funds

	Balance at 1 March 2022 £	Incoming resources £	Resources expended £	Transfers £	Balance at 28 February 2023 £
<b>Unrestricted funds</b>					
<i>General</i>					
General Funds	12,443	49,572	(35,076)	-	26,939
<i>Designated</i>					
Wolfram Syndrome Conference	43	-	(43)	-	-
Research Fund	5,193	-	(193)	-	5,000
	<u>5,236</u>	<u>-</u>	<u>(236)</u>	<u>-</u>	<u>5,000</u>
<b>Total unrestricted funds</b>	<u>17,679</u>	<u>49,572</u>	<u>(35,312)</u>	<u>-</u>	<u>31,939</u>
<b>Restricted funds</b>					
Wolfram Syndrome Conference	11,365	-	(5,476)	-	5,889
Research Fund	25,260	5,325	-	(10,094)	20,491
Breaking Down Barriers	1,592	-	(1,484)	-	108
The National Lottery Community Fund - CWB	66	-	(66)	-	-
The National Lottery Community Fund - EWB	8,325	-	(4,740)	-	3,585
Albert Hunt Trust	1,000	-	(504)	-	496
BCH NHS Contract	-	48,400	(14,728)	-	33,672
International Symposium	-	4,819	(2,600)	-	2,219
TREATWolfram	-	-	-	10,094	10,094
	<u>47,608</u>	<u>58,544</u>	<u>(29,598)</u>	<u>-</u>	<u>76,554</u>
<b>Total restricted funds</b>	<u>47,608</u>	<u>58,544</u>	<u>(29,598)</u>	<u>-</u>	<u>76,554</u>
<b>Total funds</b>	<u>65,287</u>	<u>108,116</u>	<u>(64,910)</u>	<u>-</u>	<u>108,493</u>

# Wolfram Syndrome UK

## Notes to the Financial Statements for the Year Ended 28 February 2023

	Balance at 1 March 2021 £	Incoming resources £	Resources expended £	Transfers £	Balance at 28 February 2022 £
<b>Unrestricted funds</b>					
<i>General</i>					
General Funds	21,036	26,482	(35,144)	69	12,443
<i>Designated</i>					
Wolfram Syndrome Conference	1,187	-	(1,144)	-	43
Research Fund	5,189	4	-	-	5,193
	<u>6,376</u>	<u>4</u>	<u>(1,144)</u>	<u>-</u>	<u>5,236</u>
<b>Total unrestricted funds</b>	<u>27,412</u>	<u>26,486</u>	<u>(36,288)</u>	<u>69</u>	<u>17,679</u>
<b>Restricted</b>					
Wolfram Syndrome Conference	11,323	42	-	-	11,365
Research Fund	24,766	634	(140)	-	25,260
Breaking Down Barriers	300	5,000	(3,708)	-	1,592
The National Lottery Community Fund - CWB	5,026	-	(4,890)	(69)	67
Edward Gostling Foundation	1,500	-	(1,500)	-	-
The National Lottery Community Fund - EWB	-	9,995	(1,671)	-	8,324
Albert Hunt Trust	-	1,000	-	-	1,000
	<u>42,915</u>	<u>16,671</u>	<u>(11,909)</u>	<u>(69)</u>	<u>47,608</u>
<b>Total restricted funds</b>	<u>42,915</u>	<u>16,671</u>	<u>(11,909)</u>	<u>(69)</u>	<u>47,608</u>
<b>Total funds</b>	<u>70,327</u>	<u>43,157</u>	<u>(48,197)</u>	<u>-</u>	<u>65,287</u>



## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2023

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.

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.

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

#### 19 Analysis of net assets between funds

	Unrestricted funds General £	Restricted funds £	Total funds at 28 February 2023 £
Tangible fixed assets	147	-	147
Current assets	38,910	70,664	109,574
Current liabilities	(1,230)	-	(1,230)
Total net assets	37,827	70,664	108,491

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2023

#### 20 Analysis of net funds

	At 1 March 2022 £	Financing cash flows £	At 28 February 2023 £
Cash at bank and in hand	64,907	43,159	108,066
Net debt	64,907	43,159	108,066

#### 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 - £14,658 (2022: £14,658). At the balance sheet date the amount due from Tracy Lynch was £1,131 (2022 - £Nil).

##### Gina Isherwood

(Related party of Trustee John Isherwood)

Gross wages - £9,100.00

Payment to Gem Consult for professional services, including fundraising and other activities - £6,307.50. At the balance sheet date the amount due to/from Gina Isherwood was £Nil (2022 - £Nil).