WOLFRAM SYNDROME UK

England & Wales · Charity number 1152445

Details

Other names	WSUK
Status	Registered
Legal form	CIO
Registered	2013-06-17
Register	View on the Charity Commission register

Contact

Address	9 Church Way Worthing BN13 1HD
Phone	01903211358
Email	admin@wolframsyndrome.co.uk
Website	www.wolframsyndrome.co.uk

Activities

Objects: 1)TO PROMOTE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF SUFFERERS OF WOLFRAM SYNDROME AND RELATED SYNDROMES AND THEIR FAMILIES THROUGH THE PROVISION OF SUPPORT,EDUCATION, FINANCIAL ASSISTANCE WHERE POSSIBLE AND PRACTICAL ADVICE.(2)TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC AS WELL AS THE MEDICAL PROFESSION IN ALL AREAS RELATING TO WOLFRAM SYNDROME AND RELATED SYNDROMES

Activities: WOLFRAM SYNDROME UK PROVIDES INFORMATION, FAMILY SUPPORT AND ADVICE FOR INDIVIDUALS AFFECTED, THEIR FAMILIES, CARERS AND PROFESSIONALS. WE WORK CLOSELY WITH BIRMINGHAM CHILDREN'S HOSPITAL & SOON QEH, BIRMINGHAM TO SUPPORT THE MULTI-DISCIPLINARY CLINICS FOR WS PATIENTS. WE RAISE MONEY FOR RESEARCH. WE ENDEAVOUR TO RAISE AWARENESS OF WOLFRAM SYNDROME. WE PROVIDE A 24 HOUR ANSWER-MACHINE HELP-LINE.

Downloaded from opencharities.uk/ew/1152445

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability, Other Charitable Purposes
- **Who:** Children/young People, People With Disabilities

Geography

- Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-02-28	£121,228	£139,723	-	-
2024-02-29	£136,399	£113,865	-	-
2023-02-28	£108,116	£64,911	-	-
2022-02-28	£43,157	£48,197	-	-
2021-02-28	£38,254	£46,082	-	-

Trustees

Name	Role	Appointed
John Isherwood	Chair	2019-02-22
ALAN NYE		2013-04-02
Abby Gardner		2020-04-19
PAUL LYNCH		2013-04-02
PROF TIM BARRETT		2013-04-02

Downloaded from opencharities.uk/ew/1152445

WOLFRAM SYNDROME UK

England & Wales - Charity number 1152445

Accounts

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

Contents

Reference and Administrative Details	1
Trustees' Report	2 to 8
Statement of Trustees' Responsibilities	9
Independent Examiner's Report	10
Statement of Financial Activities	11 to 12
Balance Sheet	13
Notes to the Financial Statements	14 to 26

Wolfram Syndrome UK

Reference and Administrative Details

Chairman	Mr J Isherwood
Trustees	Mr A Nye Prof T Barrett Mr P Lynch Mr J Isherwood Miss A Gardner
Senior Management / Leadership Team	Mrs T Lynch, Chief Executive Dr G Isherwood PhD, Contracts Manager
Charity Registration Number	1152445
	The charity is incorporated in England and Wales.
Registered Office	9 Church Way Tarring Worthing West Sussex BN13 1HD
Independent Examiner	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 Commisison'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 Montpelier 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.

TREATWOLFRAM

By your side

WOLFRAM SYNDROME GLOBAL AWARENESS DAY

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 it's financial performance and general reserves position. The charity has adequate financial resources and is able to manage it's 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.

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

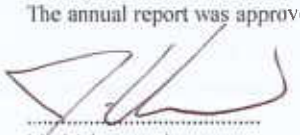
Objectives and policies

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

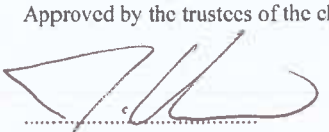
The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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 idependent 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: 28/11/25

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 £
Income and Endowments from:				
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		47,621	73,607	121,228
Expenditure on:				
Raising funds	6	(29,549)	-	(29,549)
Charitable activities	7	(27,133)	(83,041)	(110,174)
Total Expenditure		(56,682)	(83,041)	(139,723)
Net expenditure		(9,061)	(9,434)	(18,495)
Net movement in funds		(9,061)	(9,434)	(18,495)
Reconciliation of funds				
Total funds brought forward		37,569	93,457	131,026
Total funds carried forward	18	28,508	84,023	112,531

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 £
Income and Endowments from:				
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		61,345	75,054	136,399
Expenditure on:				
Raising funds	6	(48,478)	-	(48,478)
Charitable activities	7	(4,737)	(60,650)	(65,387)
Total Expenditure		(53,215)	(60,650)	(113,865)
Net income		8,130	14,404	22,534
Transfers between funds		(2,500)	2,500	-
Net movement in funds		5,630	16,904	22,534
Reconciliation of funds				
Total funds brought forward		31,939	76,553	108,492
Total funds carried forward	18	37,569	93,457	131,026

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

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 J Isherwood
Chairman and Trustee

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.

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:

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 liabilties 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.

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	1,423	-	1,423	3,859
	9,091	644	9,735	39,500

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	38,155	-	38,155	45,458
	38,530	72,307	110,837	96,399

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

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

b) Costs of trading activities

	Note	Unrestricted funds General £	Total 2025 £	Total 2024 £
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

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
		27,133	83,041	110,174	65,387

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.

11 Staff costs

The aggregate payroll costs were as follows:

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

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	4	4

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 £
Other fees to examiners		
The examining of the accounts of the charity	1,428	1,344

13 Taxation

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

14 Tangible fixed assets

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

15 Stock

	2025 £	2024 £
Stocks	967	425

16 Debtors

	2025 £	2024 £
Trade debtors	-	866
Prepayments	267	244
	267	1,110

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
	3,825	2,566

18 Funds

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

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 £
Unrestricted funds					
General					
General Funds	26,939	61,345	(53,215)	(2,500)	32,569
Designated					
Research Fund	5,000	-	-	-	5,000
Total unrestricted funds	31,939	61,345	(53,215)	(2,500)	37,569
Restricted					
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
Total restricted funds	76,554	75,054	(60,651)	2,500	93,457
Total funds	108,493	136,399	(113,866)	-	131,026

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.

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).

WOLFRAM SYNDROME UK

England & Wales - Charity number 1152445

Accounts

Charity registration number: 1152445

Wolfram Syndrome UK

Annual Report and Financial Statements

for the Year Ended 29 February 2024

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

Wolfram Syndrome UK

Contents

Reference and Administrative Details	1
Trustees' Report	2 to 8
Statement of Trustees' Responsibilities	9
Independent Examiner's Report	10
Statement of Financial Activities	11 to 12
Balance Sheet	13
Notes to the Financial Statements	14 to 26

Wolfram Syndrome UK

Reference and Administrative Details

Chairman	Mr J Isherwood
Trustees	Mr A Nye Prof T Barrett Mr P Lynch Mr J Isherwood Miss A Gardner
Senior Management / Leadership Team	Mrs T Lynch, Chief Executive Dr G Isherwood PhD, Contracts Manager
Charity Registration Number	1152445
	The charity is incorporated in England and Wales.
Registered Office	9 Church Way Tarring Worthing West Sussex BN13 1HD
Independent Examiner	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 29 February 2024.

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 2023/2024, 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 2023, WSUK successfully completed the first 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 and young people, and their parent carers and wider family members.

At the end of Y1 (i.e. Oct 2023), the WSUK Family Support Co-ordinator (FSC) was either supporting or was actively engaged with the majority (76%) of young people and their families and had delivered or was actively delivering a total of 80 support issues (e.g. supporting Education, Health and Care Plan (EHCP) applications or providing emotional support to parents). During Y1, 6 families received a home visit from the FSC.

By Oct 2023, the FSC had also successfully supported the four WS MDT clinics at BCH, which were attended by a total of 20 children / young people in person and 3 virtually (23 total; 9 of whom were new referrals) and their 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 families attended each of the WS MDT clinics during 2023 as expected, the number of DNAs was zero - a very positive achievement.

Some of WSUK's on-going activities conducted to support or inform the WS community, continue to 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.

In September 2023, WSUK held a face-to-face UK Annual Conference at a new venue which catered for many of our communities needs. The UK Conference provided the 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. Presentations both 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 (https://wolframsyndrome.co.uk/ws-conference). As part of the conference, two first aid workshops were held for a total of 24 attendees to learn Basic First Aid skills. These proved popular and will be considered for future events.

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 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.

During 2023/2024, the WSUK Adult Support Co-ordinator (ASC) continued to engage with the WS affected adult community to provide enhanced support through activities such as: -
i. Attendance at the WS Adult MDT clinics at Queen Elizabeth Hospital (QEH).
By Feb 2024, the ASC had attended a total of 4 WS MDT clinics at QEH (80% of 5 clinics held) to meet WS affected adults and their family members in person and better understand their situation, current challenges and support needs. Through attending these clinics in person, the ASC also has built strong, positive relationships with the adult clinic lead and other members of the MDT team.
ii. The Emotional Wellbeing (EWB) project for WS affected adults.
In Nov 2023, WSUK completed the EWB project, which 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. As part of this project, the ASC held personalised 1:1 monthly support sessions with 13 WS affected adults, and 4 adults have continued with these sessions beyond the end of the project. In addition, the ASC held interactive peer wellbeing support sessions to provide a safe and welcoming space for WS affected adults to connect and help each other. Wellbeing resources, on different aspects of wellbeing from a range of recognised sources, have also been made available on WSUK website for everyone in the WS community (https://wolframsyndrome.co.uk/our-projects/).
iii. On-going front-line support
In addition to the WS MDT clinics and EWB project, the ASC has supported WS affected adults and their families with a range of other issues such as accessing adult social care, housing adaptations and attending MDT meetings on EHCPs/further education. By Feb 2024, the ASC had conducted 6 home visits to help support WS affected adults, which included for example, a newly diagnosed family, a family with housing adaptation needs and supporting 2 young adults with their mental health.
Through all these activities, the ASC has successfully established strong and trusted relationships with many WS affected adults and has started building connections within the adult community for peer-to-peer support. There is a clear need for continued on-going support and therefore WSUK intends to develop new activities during 2024/25 to further engage and help the WS adult community.

Wolfram Syndrome UK

Trustees' Report

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 October 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

In February 2024, the WSUK Scientific Advisory Board (SAB) met to discuss the research proposals received for the small grant funding of £15,000. A decision was made to award these funds to a research project in Birmingham that had some links to the TREATWolfram project. The funds will be released in the next financial year (i.e. 2024/2025) due to the timing of the SAB decision in February 2024.

3 WS International Research Symposium

In April 2023, WSUK co-hosted the 8th WS International Researchers Symposium in Surrey. 30 researchers and Pharma representatives from around the world spent 2 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 chat 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 CURE4WOLFRAM Action Plan, which will be discussed at the next symposium planned for late 2024 in the UK.

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 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.

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 10th 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.

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. 80's night –

In April 2023, WSUK held its popular 80's night, which was well attended as always.

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 third WS Global Awareness Day took place on October 1st 2023, which fell the day after the annual conference. WS related information was distributed to global organisations to help raise their awareness of the condition. WSUK intends to hold the fourth WS Global Awareness Day on 1st October 2024.

Financial review

Total incoming resources for the year were £136,399 (2023: £108,116) with expenditure of £113,865 (2023: £64,911). Overall, there was a surplus for the year of £22,534 (2023: £43,205). Unrestricted funds at the year-end were £37,569 (2023: £31,937) and the restricted funds were £93,457 (2023: £76,555). Total funds for the year were £131,026 (2023: £108,492).

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 it's financial performance and general reserves position. The charity has adequate financial resources and is able to manage it's 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.

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.

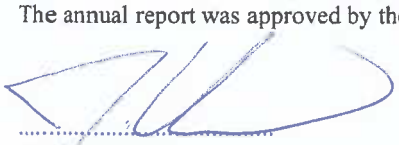
Key strategic and administrative decisions are made by agreement of the trustees, and delegated as appropriate. Day to day management of the charity is delegated to the Chief Executive, Mrs Tracy Lynch.

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 15/11/24 and signed on its behalf by:



Mr J Isherwood
Chairman and trustee

Wolfram Syndrome UK

Statement of Trustees' Responsibilities

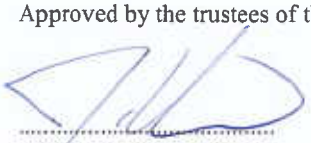
The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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 15/11/24 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 29 February 2024.

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 idependent 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.

Hodson

Matthew Hodson FCA
Independent Examiner
Hodson & Co
Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

Date: 15/11/2024

Wolfram Syndrome UK

Statement of Financial Activities for the Year Ended 29 February 2024 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

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

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 29 February 2024 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2023 £
Income and Endowments from:				
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		49,572	58,544	108,116
Expenditure on:				
Raising funds	6	(25,335)	-	(25,335)
Charitable activities	7	(9,979)	(29,597)	(39,576)
Total Expenditure		(35,314)	(29,597)	(64,911)
Net income		14,258	28,947	43,205
Net movement in funds		14,258	28,947	43,205
Reconciliation of funds				
Total funds brought forward		17,679	47,608	65,287
Total funds carried forward	18	31,937	76,555	108,492

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

The funds breakdown for 2023 is shown in note 18.

Wolfram Syndrome UK

Balance Sheet as at 29 February 2024

	Note	2024 £	2023 £
Fixed assets			
Tangible assets	14	241	147
Current assets			
Stocks	15	425	837
Debtors	16	1,110	671
Cash at bank and in hand		131,816	108,066
		133,351	109,574
Creditors: Amounts falling due within one year	17	(2,566)	(1,229)
Net current assets		130,785	108,345
Net assets		131,026	108,492
Funds of the charity:			
Restricted income funds			
Restricted funds	18	93,457	76,553
Unrestricted income funds			
Unrestricted funds		37,569	31,939
Total funds	19	131,026	108,492

The financial statements on pages 11 to 26 were approved by the trustees, and authorised for issue on 15/11/24 and signed on their behalf by:

Mr J Isherwood
Chairman and Trustee

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.

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 consistant.

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:

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 liabilties 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.

3 Income from donations and legacies

	Unrestricted funds General £	Restricted funds £	Total 2024 £	Total 2023 £
Donations and legacies;				
Donations from individuals	9,202	16,215	25,417	27,730
Grants, including capital grants;				
Grants from other charities	2,047	8,177	10,224	5,246
Regular giving and capital donations	3,859	-	3,859	501
	15,108	24,392	39,500	33,477

4 Income from other trading activities

	Unrestricted funds General £	Restricted funds £	Total funds £	Total 2023 £
Trading income;				
Sales of goods and services	279	-	279	330
Other trading income	-	50,662	50,662	48,400
Events income;				
Other events income	45,458	-	45,458	25,890
	45,737	50,662	96,399	74,620

5 Investment income

	Unrestricted funds General £	Total 2024 £	Total 2023 £
Interest receivable and similar income;			
Interest receivable on bank deposits	500	500	19

6 Expenditure on raising funds

a) Costs of generating donations and legacies

	Note	Unrestricted funds General £	Total 2024 £	Total 2023 £
Marketing and publicity		3,168	3,168	166
Allocated support costs	8	8,007	8,007	1,590
		11,175	11,175	1,756

b) Costs of trading activities

	Note	Unrestricted funds General £	Total 2024 £	Total 2023 £
Costs of goods sold		4,225	4,225	2,346
Depreciation, amortisation and other similar costs		181	181	361
Other direct costs of activities for generating funds		32,897	32,897	20,872
		37,303	37,303	23,579

7 Expenditure on charitable activities

	Note	Unrestricted funds General £	Restricted funds £	Total 2024 £	Total 2023 £
Support for WS community		185	60,766	60,951	22,419
Conference costs		-	(133)	(133)	5,475
Allocated support costs	8	-	-	-	531
Governance costs	8	4,552	17	4,569	11,151
		4,737	60,650	65,387	39,576

8 Analysis of governance and support costs

Raising funds expenditure

Support costs allocated to raising funds

	Administration costs	Total 2024	Total 2023
	£	£	£
Costs of generating donations and legacies	8,007	8,007	1,590

Governance costs

	Unrestricted funds General	Restricted funds	Total 2024	Total 2023
	£	£	£	£
Independent examiner fees				
Examination of the financial statements	1,344	-	1,344	1,452
Professional fees	13	-	13	6,457
Other governance costs	3,195	17	3,212	3,242
	4,552	17	4,569	11,151

9 Net incoming/outgoing resources

Net incoming resources for the year include:

	2024	2023
	£	£
Depreciation of fixed assets	181	361

10 Trustees remuneration and expenses

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

Mr P Lynch
£Nil (2023: £1,131) of expenses were reimbursed to Mr P Lynch during the year.

11 Staff costs

The aggregate payroll costs were as follows:

	2024 £	2023 £
Staff costs during the year were:		
Wages and salaries	66,785	37,561
Pension costs	2,004	1,070
	68,789	38,631

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:

	2024 No	2023 No
Full time employees	4	3

Contributions to the employee pension schemes for the year totalled £2,004 (2023 - £1,070).

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

12 Independent examiner's remuneration

	2024 £	2023 £
Other fees to examiners		
The examining of the accounts of the charity	1,344	1,452

13 Taxation

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

14 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 March 2023	4,457	4,457
Additions	275	275
At 29 February 2024	4,732	4,732
Depreciation		
At 1 March 2023	4,310	4,310
Charge for the year	181	181
At 29 February 2024	4,491	4,491
Net book value		
At 29 February 2024	241	241
At 28 February 2023	147	147

15 Stock

	2024 £	2023 £
Stocks	425	837

16 Debtors

	2024 £	2023 £
Trade debtors	866	427
Prepayments	244	244
	1,110	671

17 Creditors: amounts falling due within one year

	2024 £	2023 £
Trade creditors	41	59
Other taxation and social security	110	(222)
Accruals	2,415	1,392
	2,566	1,229

18 Funds

	Balance at 1 March 2023 £	Incoming resources £	Resources expended £	Transfers £	Balance at 29 February 2024 £
Unrestricted funds					
General					
General Funds	26,939	61,345	(53,215)	(2,500)	32,569
Designated					
Research Fund	5,000	-	-	-	5,000
Total unrestricted funds	31,939	61,345	(53,215)	(2,500)	37,569
Restricted funds					
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
Total restricted funds	76,554	75,054	(60,651)	2,500	93,457
Total funds	108,493	136,399	(113,866)	-	131,026

Wolfram Syndrome UK

Notes to the Financial Statements for the Year Ended 29 February 2024

	Balance at 1 March 2022 £	Incoming resources £	Resources expended £	Transfers £	Balance at 28 February 2023 £
Unrestricted funds					
General					
General Funds	12,443	49,572	(35,076)	-	26,939
Designated					
Wolfram Syndrome Conference	43	-	(43)	-	-
Research Fund	5,193	-	(193)	-	5,000
	5,236	-	(236)	-	5,000
Total unrestricted funds	17,679	49,572	(35,312)	-	31,939
Restricted					
Wolfram Syndrome Conference	11,365	-	(5,475)	-	5,890
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	-	(4,741)	-	3,584
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
Total restricted funds	47,608	58,544	(29,598)	-	76,554
Total funds	65,287	108,116	(64,910)	-	108,493

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.

19 Analysis of net assets between funds

	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	(2,215)	-	(2,215)
Total net assets	37,919	93,458	131,377

	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

20 Analysis of net funds

	At 1 March 2023 £	Financing cash flows £	At 29 February 2024 £
Cash at bank and in hand	108,066	23,750	131,816
	108,066	23,750	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 - £17,353 (2023: £14,658). At the balance sheet date the amount due to/from from Tracy Lynch was £Nil (2023 - £1,131).

Gina Isherwood
(Related party of Trustee John Isherwood)
Gross wages - £20,134 (2023: £9,100)

Payment to Gem Consult for professional services, including fundraising and other activities - £0 (2023: £6,307.50). At the balance sheet date the amount due to/from Gina Isherwood was £Nil (2023 - £Nil).

WOLFRAM SYNDROME UK

England & Wales - Charity number 1152445

Accounts

Charity registration number: 1152445

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

Contents

Reference and Administrative Details	1
Trustees' Report	2 to 8
Statement of Trustees' Responsibilities	9
Independent Examiner's Report	10
Statement of Financial Activities	11 to 12
Balance Sheet	13
Notes to the Financial Statements	14 to 26

Wolfram Syndrome UK

Reference and Administrative Details

Chairman	Mr J Isherwood
Trustees	Mr A Nye Prof T Barrett Mr P Lynch Mr J Isherwood Miss A Gardner Mr N Mistry
Senior Management / Leadership Team	Mrs T Lynch, Chief Executive Dr G Isherwood PhD, Contracts Manager
Charity Registration Number	1152445 The charity is incorporated in England and Wales.
Registered Office	9 Church Way Tarring Worthing West Sussex BN13 1HD
Independent Examiner	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.

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.



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.

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).

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 it's financial performance and general reserves position. The charity has adequate financial resources and is able to manage it's 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.

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

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 idependent 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: 13/11/2023

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 £
Income and Endowments from:				
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		49,572	58,544	108,116
Expenditure on:				
Raising funds	6	(25,335)	(17,308)	(42,643)
Charitable activities	7	(9,979)	(12,289)	(22,268)
Total Expenditure		(35,314)	(29,597)	(64,911)
Net income		14,258	28,947	43,205
Net movement in funds		14,258	28,947	43,205
Reconciliation of funds				
Total funds brought forward		17,679	47,608	65,287
Total funds carried forward	18	31,937	76,555	108,492

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 £
Income and Endowments from:				
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		26,486	16,671	43,157
Expenditure on:				
Raising funds	6	(21,263)	-	(21,263)
Charitable activities	7	(15,025)	(11,909)	(26,934)
Total Expenditure		(36,288)	(11,909)	(48,197)
Net (expenditure)/income		(9,802)	4,762	(5,040)
Transfers between funds		69	(69)	-
Net movement in funds		(9,733)	4,693	(5,040)
Reconciliation of funds				
Total funds brought forward		27,412	42,915	70,327
Total funds carried forward	18	17,679	47,608	65,287

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.

Balance Sheet as at 28 February 2023

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

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.

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 consistant.

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:

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 liabilties 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.

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
	28,658	4,819	33,477	20,497

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
	20,895	53,725	74,620	22,656

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

7 Expenditure on charitable activities

	Note	Unrestricted funds Designated £	Unrestricted funds General £	Restricted funds £	Total 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
		43	9,936	12,289	22,268

	Note	Total 2022 £
Support for WS community		11,482
Conference costs		(1)
Allocated support costs	8	375
Governance costs	8	15,078
		26,934

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.

11 Staff costs

The aggregate payroll costs were as follows:

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

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	3	1

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 £
Other fees to examiners		
The examining of the accounts of the charity	1,452	1,200

13 Taxation

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

14 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 March 2022	4,457	4,457
At 28 February 2023	4,457	4,457
Depreciation		
At 1 March 2022	3,948	3,948
Charge for the year	362	362
At 28 February 2023	4,310	4,310
Net book value		
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

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
	1,229	3,101

18 Funds

	Balance at 1 March 2022 £	Incoming resources £	Resources expended £	Transfers £	Balance at 28 February 2023 £
Unrestricted funds					
General					
General Funds	12,443	49,572	(35,076)	-	26,939
Designated					
Wolfram Syndrome Conference	43	-	(43)	-	-
Research Fund	5,193	-	(193)	-	5,000
	5,236	-	(236)	-	5,000
Total unrestricted funds	17,679	49,572	(35,312)	-	31,939
Restricted funds					
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
Total restricted funds	47,608	58,544	(29,598)	-	76,554
Total funds	65,287	108,116	(64,910)	-	108,493

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 £
Unrestricted funds					
General					
General Funds	21,036	26,482	(35,144)	69	12,443
Designated					
Wolfram Syndrome Conference	1,187	-	(1,144)	-	43
Research Fund	5,189	4	-	-	5,193
	6,376	4	(1,144)	-	5,236
Total unrestricted funds	27,412	26,486	(36,288)	69	17,679
Restricted					
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
Total restricted funds	42,915	16,671	(11,909)	(69)	47,608
Total funds	70,327	43,157	(48,197)	-	65,287

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

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).

WOLFRAM SYNDROME UK

England & Wales - Charity number 1152445

Accounts

Charity registration number: 1152445

Wolfram Syndrome UK

Annual Report and Financial Statements

for the Year Ended 28 February 2022

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

Wolfram Syndrome UK

Contents

Reference and Administrative Details	1
Trustees' Report	2 to 6
Statement of Trustees' Responsibilities	7
Independent Examiner's Report	8
Statement of Financial Activities	9 to 10
Balance Sheet	11
Notes to the Financial Statements	12 to 24

Wolfram Syndrome UK

Reference and Administrative Details

Chairman	J Isherwood
Trustees	Mr A Nye Prof T Barrett Mr P Lynch J Isherwood A Gardner
Senior Management / Leadership Team	T Lynch, Chief Executive
Charity Registration Number	1152445
	The charity is incorporated in England and Wales.
Registered Office	9 Church Way Tarring Worthing West Sussex BN13 1HD
Independent Examiner	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 2022.

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 90 diagnosed sufferers in the UK. This number is rising and expected to reach 150 due to improvements in the diagnosis of partial Wolfram. WSUK exists to meet these needs for the WS community. 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, advice and guidance.

Further practical and emotional benefit is provided by WSUK to families living with WS in the form of an annual conference, interim day clinics and family meetings. It is intended that these are organised at little or no cost for families and individuals to help maximise participation. WSUK will also try to organise "take a break" opportunities for parents and carers at an affordable cost. WSUK endeavours to fund & organise social events that enable members of the WS community to meet to build relationships and provide peer support. It is important for the WS community to have opportunities to meet in between annual conferences and WSUK intends to provide regular social events at venues around the country to meet that need or via regular digital sessions. For the benefit of current and future sufferers the level of awareness, debate and research amongst 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.

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.

Wolfram Syndrome UK

Trustees' Report

Achievements and performance

The Covid-19 pandemic continued to have an influence on the activities of WSUK during the year and continued to be a key focus on the support that WSUK has provided to our community under these constantly changing circumstances. Specific support activities that have been implemented include:

- The continuation of online social sessions to allow the community to interact and provide social contact throughout the lockdown periods & beyond.
- The recruitment of an Adult Support Co-ordinator at the start of the autumn to provide enhanced on-going support for our affected adults/their parent carers.
- The start of an Emotional Wellbeing project for affected WS adults with the creation of 2 new webpages to run alongside 1:1 & peer group support sessions.

Due to the pandemic & continued restrictions, the WS 10th Annual conference was once again held as a virtual event over 2 Saturdays in September attracting more members of the WS community, as well as clinicians and researchers from around the world. This was the second time this type of virtual event has been held for the WS community. Each conference presentation had a separate registration link, which enabled participants to select the specific sessions that they were interested in joining. Each session was also uploaded to the WSUK website after the event.

The virtual conference was successful and proved popular again, particularly with those who are unable to attend a live WS conference due to cost and/or travel difficulties, but are able to participate on-line. The involvement of global members of the WS community enabled WSUK to continue to expand its database (with those who consented). Moving forward, WSUK will hold both a virtual global conference and a face-to-face UK conference, and the latter will be livestreamed to the WS community.

WSUK continues to support the TREATWolfram clinical trial which has a total of 63 recruits across the UK and three other international sites. The COVID pandemic led to delays in trial recruitment, which was finally closed on 1st November 2021. The first young people, who were recruited at Birmingham Children's Hospital, have now completed the trial and had their last patient visits. There is a Data Monitoring Committee meeting this Autumn where the 'unblinded' data will be reviewed. Hopefully, the Committee will confirm that the trial should continue as planned.

The final payment from WSUK to support patient visit costs for the trial remains deferred as a result of the delays to recruitment and hospital visits due to Covid-19. These funds remain restricted for this and any future trials. Should any funds already provided by WSUK remain at the end of the trial, they will be reimbursed to the charity, for future research use.

Our monthly donors continued with their regular contributions which were hugely appreciated during the second year of pandemic restrictions. Fundraising activities were conducted throughout the year by the WS community and its supporters. Examples include i) Students from Dublin University's Maths Society, who conducted a 'March in March', where they walked or cycled as much as possible, donating 1 Euro for each km they completed; ii) A parent held a charity bake sale at their offices, ii) A solicitors', local to the WSUK office, held a dress down day; . iv) The brother of an affected young adult ran his first Brighton Marathon; and v) A WS affected teenager ran the Twyford 5k with her sighted guide. WSUK also received a donation in memory of a WS affected adult, who was not previously known to the charity, which was greatly appreciated by everyone at WSUK.

WSUK held two major annual fundraising events during the year. The 8th annual Golf Day was held in October, a few months later than planned. Despite bad weather and a fuel shortage, all teams were able to participate and raised more funds than expected. In addition, the popular WSUK 80's night returned for the 5th time in October and also raised more than anticipated. Following this success, WSUK intends to hold both events during 2022/23.

WSUK also continued to fundraise by selling WSUK branded items (such as face coverings, water bottles and pens) at fundraising events, and through the WSUK website and social media pages.






The Caregivers Wellbeing Pilot Project, funded by a grant from The National Lottery Community Fund (TNLCF), Awards for All, was completed in November 2021, the finish date agreed with TNLCF, (2 carer participants completed their wellbeing activities after November, with agreement from TNLCF). The feedback received from all 20 carer participants was extremely positive, with participants reporting that the pilot has helped to improve their i) physical wellbeing, ii) emotional wellbeing and/or iii) social isolation. Following this success, WSUK has applied for further grant funding to continue to help support the wellbeing of WS carers.

COMMUNITY FUND

At the start of 2021/22, WSUK received a second grant from the Breaking Down Barriers (BDB) initiative, run by Alstrom Syndrome UK and funded by the Sylvia Adams Charitable Trust. In this year 2 BDB project, WSUK has created a project-specific hub on the WSUK website (https://wolframsyndrome.co.uk/breaking-down-barriersbdb/), to provide information for the WS community in English, Urdu and Arabic. In addition, WSUK has recorded video clips with members of the WS community on different aspects of living with WS (e.g. living independently, leisure activities and parents' views of WS) which are being made available on the WSUK website (https://wolframsyndrome.co.uk/bdb-community-videos/).

BREAKING DOWN BARRIERS
understanding genetics together

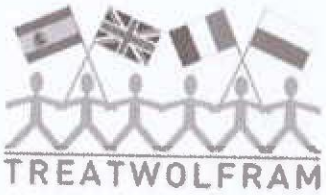
In January 2022, WSUK received a grant from TNLCF, Awards for all, to conduct a new project to help empower WS affected adults to improve their emotional wellbeing. WSUK has developed a project specific webpage (https://wolframsyndrome.co.uk/our-projects/) to provide information from a range of recognised sources on different aspects of wellbeing. In addition, participating WS affected adults will receive on-going personalised support from WSUK to help improve their wellbeing.

WSUK continues to deliver the quarterly newsletter to the WS community and its supporters, which includes regular updates on a range of topics such as, the TREATWolfram clinical trial. Each newsletter is sent by email to members of the community, uploaded on the WSUK website and shared on our social media. The pictures included in the digital version have a text alternative for visually impaired (VI) members who use a screen reader. An audio version is also made available for visually impaired (VI) members. In addition, WSUK sends a large font printed copy to a few members, where specifically requested.

Wolfram Syndrome UK

Trustees' Report

2021 saw the first ever Wolfram Syndrome Global Awareness Day (WSGAD) take place to help raise the awareness of WS among healthcare professionals and the broader public. 1st October 2021 was specifically chosen for the WSGAD as it corresponds to the date that the paper on the identification of the WSf1 gene was first published. WSUK initiated the event and involved 7 other WS patient support organisations from different countries. On the day, there was a social media 'baton relay', where participants from each country posted information and updates at 10.00am local time. Global organisations in the fields or Ophthalmology, Diabetes and Endocrinology received relevant information to help them raise awareness of WS to their members. Following the success of this new initiative, the WSGAD will take place on 1st October each year, and the planning for the 2022 event is already underway.







Financial review

Total incoming resources for the year were £43,157 (2021: £38,254) with expenditure of £48,197 (2021: £46,082). Overall, there was a deficit for the year of £5,040 (2021: deficit £7,828). Unrestricted funds at the year-end were £18,823 (2021: £27,412) and the restricted funds were £46,464 (2021: £42,915). Total funds for the year were £65,287 (2021: £70,327).

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 it's financial performance and general reserves position. The charity has adequate financial resources and is able to manage it's 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.

The Covid-19 virus has had an impact on the Charity's activities. Whilst it is difficult to evaluate with any certainty the potential outcome on the charity's activities, the trustees have a reasonable expectation that the charity will continue in operational existence for the foreseeable future.

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

Wolfram Syndrome UK

Trustees' Report

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.

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.

Small companies provision statement

This report has been prepared in accordance with the small companies regime under the Companies Act 2006.

The annual report was approved by the trustees of the charity on 01/09/17 and signed on its behalf by:

.....

J Isherwood
Chairman and trustee

Wolfram Syndrome UK

Statement of Trustees' Responsibilities

The trustees (who are also the directors of Wolfram Syndrome UK for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations. The report and accounts have been prepared in accordance with the provisions in the Companies Act 2006 relating to small companies.

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of its incoming resources and application of resources, including its income and expenditure, 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 UK 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 charitable company will continue in business.

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the trustees of the charity on 01/05/22 and signed on its behalf by:

.....

J Isherwood
Chairman and trustee

Wolfram Syndrome UK

Independent Examiner's Report to the trustees of Wolfram Syndrome UK ("the Company")

I report to the charity trustees on my examination of the accounts of the Company for the year ended 28 February 2022.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of Wolfram Syndrome UK are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

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

1. accounting records were not kept in respect of Wolfram Syndrome UK as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

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

.....

Matthew Hodson FCA
Independent Examiner

Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

Date: 01/09/2022

Wolfram Syndrome UK

Statement of Financial Activities for the Year Ended 28 February 2022 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

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

The notes on pages 12 to 24 form an integral part of these financial statements.

Wolfram Syndrome UK

Statement of Financial Activities for the Year Ended 28 February 2022 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2021 £
Income and Endowments from:				
Donations and legacies	3	7,307	18,984	26,291
Other trading activities	4	11,934	-	11,934
Investment income	5	29	-	29
Total Income		19,270	18,984	38,254
Expenditure on:				
Raising funds	6	(6,695)	(4,076)	(10,771)
Charitable activities	7	(12,485)	(22,826)	(35,311)
Total Expenditure		(19,180)	(26,902)	(46,082)
Net income/(expenditure)		90	(7,918)	(7,828)
Transfers between funds		(29,034)	29,034	-
Net movement in funds		(28,944)	21,116	(7,828)
Reconciliation of funds				
Total funds brought forward		56,356	21,799	78,155
Total funds carried forward	17	27,412	42,915	70,327

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

The funds breakdown for 2021 is shown in note 17.

Wolfram Syndrome UK

(Registration number: CLUB)
Balance Sheet as at 28 February 2022

	Note	2022 £	2021 £
Fixed assets			
Tangible assets	13	509	336
Current assets			
Stocks	14	932	1,235
Debtors	15	2,041	926
Cash at bank and in hand		64,907	69,931
		67,880	72,092
Creditors: Amounts falling due within one year	16	(3,102)	(2,101)
Net current assets		64,778	69,991
Net assets		65,287	70,327
Funds of the charity:			
Restricted income funds			
Restricted funds	17	47,608	42,915
Unrestricted income funds			
Unrestricted funds		17,679	27,412
Total funds	18	65,287	70,327

For the financial year ending 28 February 2022 the charity was entitled to exemption from audit under section 479A of the Companies Act 2006 relating to subsidiary companies.

Directors' responsibilities:

- The members have not required the charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

The financial statements on pages 9 to 24 were approved by the trustees, and authorised for issue on 01/09/22 and signed on their behalf by:

J Isherwood
Chairman and trustee

The notes on pages 12 to 24 form an integral part of these financial statements.

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.

Exemption from preparing a cash flow statement
The charity opted to early adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

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.

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 consistant.

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's 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:

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 liabilties 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.

3 Income from donations and legacies

	Unrestricted funds General £	Restricted funds £	Total 2022 £	Total 2021 £
Donations and legacies;				
Donations from individuals	3,174	676	3,850	5,907
Grants, including capital grants;				
Grants from other charities	-	15,995	15,995	18,450
Regular giving and capital donations	652	-	652	1,934
	3,826	16,671	20,497	26,291

Of total income from donations and legacies in 2021, £18,984 was in restricted funds.

4 Income from other trading activities

	Unrestricted funds General £	Total funds £	Total 2021 £
Trading income;			
Sales of goods and services	331	331	737
Events income;			
Other events income	22,325	22,325	11,197
	22,656	22,656	11,934

Of total income from other trading activities in 2021, £Nil was in restricted funds.

5 Investment income

	Unrestricted funds General £	Total 2022 £	Total 2021 £
Interest receivable and similar income;			
Interest receivable on bank deposits	4	4	29

6 Expenditure on raising funds

a) Costs of generating donations and legacies

	Note	Unrestricted funds General £	Total 2022 £	Total 2021 £
Allocated support costs	8	1,484	1,484	954

b) Costs of trading activities

	Note	Unrestricted funds General £	Total 2022 £	Total 2021 £
Costs of goods sold		1,786	1,786	1,605
Depreciation, amortisation and other similar costs		406	406	286
Other direct costs of activities for generating funds		17,587	17,587	7,926
		19,779	19,779	9,817

Of the total costs for raising funds in 2021, £4,076 were out of restricted funds.

7 Expenditure on charitable activities

	Note	Unrestricted funds Designated £	General £	Restricted funds £	Total 2022 £
Support for WS community		1,144	69	10,269	11,482
Conference costs		-	-	(1)	(1)
Allocated support costs	8	-	-	375	375
Governance costs	8	-	13,812	1,266	15,078
		1,144	13,881	11,909	26,934

	Note	Total 2021 £
Support for WS community		19,329
Conference costs		573
Allocated support costs	8	214
Governance costs	8	15,195
		35,311

Of the total costs for charitable activities in 2021, £22,826 were out of restricted funds.

8 Analysis of governance and support costs

Raising funds expenditure

Costs of generating donations and legacies

	Unrestricted General £	Total 2022 £	Total 2021 £
Governance costs	1,484	1,484	954

Support costs allocated to raising funds

	Governance costs £	Total 2022 £	Total 2021 £
Costs of generating donations and legacies	1,484	1,484	954

Governance costs

	Unrestricted funds General £	Restricted funds £	Total 2022 £	Total 2021 £
Independent examiner fees				
Examination of the financial statements	1,200	-	1,200	900
Professional fees	11,646	-	11,646	10,411
Other governance costs	966	1,266	2,232	3,884
	13,812	1,266	15,078	15,195

9 Net incoming/outgoing resources

Net outgoing resources for the year include:

	2022 £	2021 £
Depreciation of fixed assets	406	286

10 Staff costs

The aggregate payroll costs were as follows:

	2022 £	2021 £
Staff costs during the year were:		
Wages and salaries	19,329	6,604
Social security costs	-	269
Pension costs	440	262
	19,769	7,135

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:

	2022 No	2021 No
Full time employees	1	1

Contributions to the employee pension schemes for the year totalled £440 (2021 - £262).

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

11 Independent examiner's remuneration

	2022 £	2021 £
Other fees to examiners		
The examining of the accounts of the charity	1,200	900

12 Taxation

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

13 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 March 2021	3,878	3,878
Additions	579	579
At 28 February 2022	4,457	4,457
Depreciation		
At 1 March 2021	3,542	3,542
Charge for the year	406	406
At 28 February 2022	3,948	3,948
Net book value		
At 28 February 2022	509	509
At 28 February 2021	336	336

14 Stock

	2022 £	2021 £
Stocks	932	1,235

15 Debtors

	2022 £	2021 £
Trade debtors	-	10
Prepayments	309	243
Other debtors	1,732	673
	2,041	926

16 Creditors: amounts falling due within one year

	2022 £	2021 £
Trade creditors	1,759	706
Other taxation and social security	107	495
Accruals	1,236	900
	3,102	2,101

17 Funds

	Balance at 1 March 2021 £	Incoming resources £	Resources expended £	Transfers £	Balance at 28 February 2022 £
Unrestricted funds					
General					
General Funds	21,036	26,482	(35,144)	69	12,443
Designated					
Wolfram Syndrome Conference	1,187	-	(1,144)	-	43
Research Fund	5,189	4	-	-	5,193
	6,376	4	(1,144)	-	5,236
Total unrestricted funds	27,412	26,486	(36,288)	69	17,679
Restricted funds					
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
Total restricted funds	42,915	16,671	(11,909)	(69)	47,608
Total funds	70,327	43,157	(48,197)	-	65,287

Wolfram Syndrome UK

Notes to the Financial Statements for the Year Ended 28 February 2022

	Balance at 1 March 2020 £	Incoming resources £	Resources expended £	Transfers £	Balance at 28 February 2021 £
Unrestricted funds					
General					
General Funds	8,114	19,241	(19,180)	12,861	21,036
Designated					
Wolfram Syndrome Conference	11,421	-	-	(10,234)	1,187
Research Fund	36,821	29	-	(31,661)	5,189
	48,242	29	-	(41,895)	6,376
Total unrestricted funds	56,356	19,270	(19,180)	(29,034)	27,412
Restricted					
Wolfram Syndrome Conference	7,094	-	(573)	4,802	11,323
Research Fund	-	534	-	24,232	24,766
Chalk Cliff Trust	-	3,000	(3,000)	-	-
Breaking Down Barriers	4,740	-	(4,590)	150	300
The National Lottery Community Fund - CWB	9,965	-	(4,789)	(150)	5,026
Edward Gostling Foundation	-	5,500	(4,000)	-	1,500
NLCF/HMG Fund	-	9,950	(9,950)	-	-
Total restricted funds	21,799	18,984	(26,902)	29,034	42,915
Total funds	78,155	38,254	(46,082)	-	70,327

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

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.

18 Analysis of net assets between funds

	Unrestricted funds General	Restricted funds	Total funds at 28 February 2022
	£	£	£
Current assets	21,925	46,464	68,389
Current liabilities	(3,102)	-	(3,102)
Total net assets	18,823	46,464	65,287

19 Analysis of net funds

	At 1 March 2021	Financing cash flows	At 28 February 2022
	£	£	£
Cash at bank and in hand	69,931	(5,024)	64,907
Net debt	69,931	(5,024)	64,907

20 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 (2020: £6,603). At the balance sheet date the amount due to/from Tracy Lynch was £Nil (2021 - £Nil).

Gina Isherwood
(Related party of Trustee John Isherwood)
Payment to Gem Consult for professional services, including fundraising and other activities - £14,062.50. At the balance sheet date the amount due to/from Gina Isherwood was £Nil (2021 - £Nil).

Paul Lynch
(Trustee)
Costs for use of home as office - £864. At the balance sheet date the amount due to/from Paul Lynch was £Nil (2021 - £Nil).

WOLFRAM SYNDROME UK

England & Wales - Charity number 1152445

Accounts

Charity registration number: 1152445

Wolfram Syndrome UK

(A company limited by share capital)

Annual Report and Financial Statements

for the Year Ended 28 February 2021

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

Wolfram Syndrome UK

Contents

Reference and Administrative Details	1
Trustees' Report	2 to 7
Statement of Trustees' Responsibilities	8
Independent Examiner's Report	9
Statement of Financial Activities	10 to 11
Balance Sheet	12
Notes to the Financial Statements	13 to 25

Wolfram Syndrome UK

Reference and Administrative Details

Chairman	J Isherwood
Trustees	Mr A Nye Prof T Barrett Mr P Lynch J Isherwood A Gardner
Senior Management Team	T Lynch, Chief Executive
Principal Office	9 Church Way Tarring Worthing West Sussex BN13 1HD
Charity Registration Number	1152445
Independent Examiner	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 2021.

Objectives and activities

Objects and aims

The charity's object and principal activities are to promote and protect the physical and mental health of sufferers of Wolfram Syndrome and related syndromes and their families through the provision of financial assistance, support, education and practical advice. To advance the education of the general public in all areas relating to Wolfram Syndrome and related syndromes.

Wolfram Syndrome 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 90 diagnosed sufferers in the UK. This number is rising and expected to reach 150 due to improvements in the diagnosis of partial Wolfram. WSUK exists to meet these needs for the WS community. 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 raise 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 maintain a voluntary register and distribute information about its aims, objectives and activities. WSUK provide direct and practical benefit through information, advice and guidance.

Further practical and emotional benefit is provided by WSUK to families living with WS in the form of an annual conference, interim day clinics and family meetings. It is intended that these are organised at little or no cost to help maximise participation. WSUK will also try to organise "take a break" opportunities for parents and carers at an affordable cost. WSUK endeavour to fund & organise social events that enable families and those affected to meet. It is important for families to have opportunities to meet in between annual conferences and WSUK intends to provide regular social events at venues around the country to meet that need or via regular digital sessions. For the benefit of current and future sufferers the level of awareness, debate and research amongst 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

The Covid-19 pandemic has had a significant influence on the activities of WSUK during the year and has been a key focus on the support that WSUK has provided to our community under these difficult circumstances. Specific support activities that have been implemented include:

- Running monthly webinars involving medical professionals to provide specific and tailored advice to our community on a range of topics including how to interpret governmental advice and specific health impacts. The platform allowed members to ask questions of relevance to their circumstances.
- Setting up online social sessions to allow the community to interact and provide social contact throughout the lockdown periods.
- Adding a Covid-19 news page to the WSUK website. This page includes helpful information, advice and updates (for example the recordings of Q&A WSUK webinars with WS medical professionals), and links to other recognised expert organisations / sources (e.g. NHS, government), which helps to keep the WS community and their families informed on issues related to the pandemic.

Due to the pandemic, our 9th Annual conference was held as a virtual event over 2 Saturdays attracting more members of the WS Community as well as clinicians from around the world. This was the first time this type of event has been held for the Wolfram Syndrome community. Each presentation included in the event had a separate registration link, which enabled participants to review the agenda sent in advance of the event and select the specific sessions that they were interested in joining. The involvement of global members of the WS community enabled WSUK to expand its database with those who consented to receive communications from the charity. The virtual conference was successful and proved popular, particularly with those who are unable to attend a live WS conference due to cost and travel but were able to participate on-line. Moving forward, WSUK will be holding both a virtual conference and a face-to-face conference.

Presentations were uploaded to the website from both virtual events.

WSUK continues to support the TREATWolfram clinical trial which currently has 15 UK recruits to date, and 31 in total when the three other international sites are included. The trial has been impacted by the pandemic which has led to a delay in recruitment and a downward revision to total numbers due to a drop in eligible patients. The UK now aims to recruit 27 affected individuals (14 children and 13 adults), out of a planned total of 46, with a new target of 64 (originally 70) for the whole trial. The other countries in the trial will endeavour to recruit the remaining patients required. The final payment from WSUK has currently been deferred as there have been the delays to recruitment and hospital visits due to Covid-19. The remaining funds will remain designated for this and future trials. Any funds remaining at the end of the trial will be reimbursed to WSUK, overseen by the University of Birmingham and the Clinical Trials Team for future research use.

Due to the pandemic and associated restrictions that came into effect on 24th March 2020, fundraising opportunities and income were greatly reduced. Fortunately, our monthly donors continued with their regular contributions which were hugely appreciated. In April, one of our members and her carer took part in a 2.6 challenge, part of a national fundraising event to replace the London Marathon and in June a family friend of another WS member had her head shaved in aid of WSUK. Our annual Golf Day unfortunately had to be cancelled but we were able to hold an online auction of some of the prizes already collected, which raised much needed funds. In December, the Great Uncle of one of our younger members sold some of his woodcraft at a stall in his local shopping centre.

WSUK continued to fundraise by selling our WSUK branded items through our website & social media pages. In the middle of December 2020, we signed up with a company that produces photobooks and delivers them free of charge anywhere around the world. For each book produced from orders using the WSUK link, the charity receives 50% of that order as a donation.





The grant for our Caregivers Wellbeing Project, funded by the National Lottery Community Fund, was unable to finish in 2020 due to the National Lockdown and restrictions imposed. 13 of our 20 Caregivers were able to start their wellbeing activities and three of those were able to complete before the end of the Financial Year. This project intends to complete by the end of the Financial Year 2021/22.

During 2020, WSUK completed the Year 1 Breaking Down Barriers project, through a grant received from the Breaking Down Barriers (BDB) initiative, run by Alstrom Syndrome UK and funded by the Sylvia Adams Trust. In year 1, WSUK, consulted with 20 of their members who are from ethnic minority communities to try and understand more about their needs. Through this consultation, WSUK has been able to increase its engagement with ethnic minority communities - numbers in the WSUK database increased by 160%, while 85% who were not previously aware of the charity are now on the distribution list. In addition, a proportion of the grant funded operational activities, including a 12-month Zoom subscription to help WSUK connect with the WS community and with each other during the restrictions. WSUK have been awarded a year 2 BDB project, which aims to build on the success of the year 1 project. The grant will be paid at the start of year 21/22.

In July WSUK were awarded a grant from the National Lottery and HM Government Coronavirus Community Support Fund to provide wellbeing support to our community. WSUK put together a 'Wellbeing Pack' for each WS member. These packs were gender and age specific, split into categories: 13 and under, 14-25 Male, 14-25 Female, 26+ Male, 26+ Female, with items tailored to each group. The packs included a treat, items to aid mental wellbeing, a pampering item, an Amazon Echo dot and useful items such as hand sanitiser, with the under 13's also receiving age appropriate tactile and sensory items. 62 packs were sent out in total. In addition, each member received a smaller pack that was sent out at Christmas which included a healthy chocolate bar, hand sanitiser and a small bear.

HM Government | In partnership with THE NATIONAL LOTTERY COMMUNITY FUND





WSUK was also awarded grant funding from Chalk Cliff Trust and The Edward Gostling Foundation which helped towards costs for providing enhanced front-line support services to the WS community required during the pandemic, and the purchase of WSUK branded facemasks that we were able to send out to each member of our community and one parent/carer where applicable.

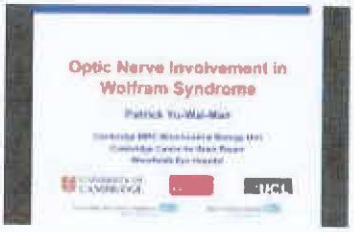
Grant funding also helped the purchase of some Distance Aware badges that were also sent out as the first lockdown was eased.




The quarterly newsletter continues to be delivered to subscribers, which includes regular updates on the TREATWolfram clinical trial. Each newsletter is sent by email to the community and is uploaded on the website and shared on social media pages. An audio version for our visually impaired (VI) members is also made available. The pictures included in the digital version have a text alternative for VI members that use a screen reader.

Finally, WSUK was pleased to welcome a new Trustee, Abby Gardner, at the start of the year. Abby is a WS affected young adult so is ideal for being able to express the views of the community WSUK is trying to help and has already been of great support to the charity.

TREATWOLFRAM



WOLFRAM SYNDROME UK
Inform, Support, CURE

Financial review

Total incoming resources for the year were £38,254 (2020: £61,187) with expenditure of £46,082 (2020: £45,490). Overall, there was a deficit for the year of £7,828 (2020: surplus of £15,697). Unrestricted funds at the year end were £27,412 (2020: £56,356) and restricted funds were £42,915 (2020: £21,799). Total funds for the year were £70,327 (2019: 78,155).

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 it's financial performance and general reserves position. The charity has adequate financial resources and is able to manage it's 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.

The Covid-19 virus has had an impact on the Charity's activities, largely with a reduction in fundraising during the financial year. Whilst it is difficult to evaluate with any certainty the potential outcome on the charity's activities, the trustees have a reasonable expectation that the charity will continue in operational existence for the foreseeable future.

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.

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.

Small companies provision statement

This report has been prepared in accordance with the small companies regime under the Companies Act 2006.

The annual report was approved by the trustees of the charity on 5/11/21 and signed on its behalf by:

.....

J Isherwood
Chairman and Trustee

Wolfram Syndrome UK

Statement of Trustees' Responsibilities

The trustees (who are also the directors of Wolfram Syndrome UK for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of its incoming resources and application of resources, including its income and expenditure, 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 UK 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 charitable company will continue in business.

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the trustees of the charity on 5/11/21 and signed on its behalf by:

.....

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 2021 which are set out on pages 10 to 25.

Respective responsibilities of trustees and examiner

As the charity's trustees of Wolfram Syndrome UK (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of Wolfram Syndrome UK are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

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

1. accounting records were not kept in respect of Wolfram Syndrome UK as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

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

.....

Matthew Hodson FCA
Independent Examiner

Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

Date: 5/11/2021

Wolfram Syndrome UK

Statement of Financial Activities for the Year Ended 28 February 2021 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2021 £
Income and Endowments from:				
Donations and legacies	3	7,307	18,984	26,291
Other trading activities	4	11,934	-	11,934
Investment income	5	29	-	29
Total Income		19,270	18,984	38,254
Expenditure on:				
Raising funds	6	(6,695)	(4,076)	(10,771)
Charitable activities	7	(12,485)	(22,826)	(35,311)
Total Expenditure		(19,180)	(26,902)	(46,082)
Net income/(expenditure)		90	(7,918)	(7,828)
Transfers between funds		(29,034)	29,034	-
Net movement in funds		(28,944)	21,116	(7,828)
Reconciliation of funds				
Total funds brought forward		56,356	21,799	78,155
Total funds carried forward	17	27,412	42,915	70,327

The notes on pages 13 to 25 form an integral part of these financial statements.

Wolfram Syndrome UK

Statement of Financial Activities for the Year Ended 28 February 2021 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2020 £
Income and Endowments from:				
Donations and legacies	3	16,351	22,273	38,624
Other trading activities	4	21,496	1,000	22,496
Investment income	5	67	-	67
Total Income		37,914	23,273	61,187
Expenditure on:				
Raising funds	6	(14,058)	(3,742)	(17,800)
Charitable activities	7	(19,525)	(8,165)	(27,690)
Total Expenditure		(33,583)	(11,907)	(45,490)
Net income		4,331	11,366	15,697
Transfers between funds		1,142	(1,142)	-
Net movement in funds		5,473	10,224	15,697
Reconciliation of funds				
Total funds brought forward		50,883	11,575	62,458
Total funds carried forward	17	56,356	21,799	78,155

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

The funds breakdown for 2020 is shown in note 17.

Wolfram Syndrome UK

(Registration number: CLUB)
Balance Sheet as at 28 February 2021

	Note	2021 £	2020 £
Fixed assets			
Tangible assets	13	336	403
Current assets			
Stocks	14	1,235	456
Debtors	15	926	988
Cash at bank and in hand		69,931	77,772
		72,092	79,216
Creditors: Amounts falling due within one year	16	(2,101)	(1,464)
Net current assets		69,991	77,752
Net assets		70,327	78,155
Funds of the charity:			
Restricted income funds			
Restricted funds	17	42,915	21,799
Unrestricted income funds			
Unrestricted funds		27,412	56,356
Total funds	18	70,327	78,155

For the financial year ending 28 February 2021 the charity was entitled to exemption from audit under section 479A of the Companies Act 2006 relating to subsidiary companies.

Directors' responsibilities:

- The members have not required the charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

The financial statements on pages 10 to 25 were approved by the trustees, and authorised for issue on 5/11/21..... and signed on their behalf by:

.....

J Isherwood
Chairman and Trustee

The notes on pages 13 to 25 form an integral part of these financial statements.

Wolfram Syndrome UK

Notes to the Financial Statements for the Year Ended 28 February 2021

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

These financial statements were authorised for issue by the trustees on 5 November 2021.

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) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). They also comply with the Companies Act 2006 and Charities Act 2011.

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.

Exemption from preparing a cash flow statement
The charity opted to early adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

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.

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 consistant.

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's 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:

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's 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 liabilties 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.

3 Income from donations and legacies

	Unrestricted funds General £	Restricted funds £	Total 2021 £	Total 2020 £
Donations and legacies;				
Donations from individuals	5,373	534	5,907	18,083
Grants, including capital grants;				
Grants from other charities	-	18,450	18,450	19,909
Regular giving and capital donations	1,934	-	1,934	632
	7,307	18,984	26,291	38,624

Of the total donations and legacies income in 2020, £22,273 was in restricted funds.

4 Income from other trading activities

	Unrestricted funds General £	Total funds £	Total 2020 £
Trading income;			
Sales of goods and services	737	737	301
Events income;			
Other events income	11,197	11,197	22,195
	11,934	11,934	22,496

Of the income from other trading activities in 2020, £1,000 was in retricted funds.

5 Investment income

	Unrestricted funds General £	Total 2021 £	Total 2020 £
Interest receivable and similar income;			
Interest receivable on bank deposits	29	29	67

All investment income is derived from unrestricted funds.

6 Expenditure on raising funds

a) Costs of generating donations and legacies

	Note	Unrestricted funds General £	Restricted funds £	Total 2021 £	Total 2020 £
Marketing and publicity		-	-	-	6,221
Allocated support costs	8	878	76	954	1,961
		878	76	954	8,182

b) Costs of trading activities

	Note	Unrestricted funds General £	Restricted funds £	Total 2021 £	Total 2020 £
Costs of goods sold		1,605	-	1,605	717
Depreciation, amortisation and other similar costs		286	-	286	106
Other direct costs of activities for generating funds		3,926	4,000	7,926	8,795
		5,817	4,000	9,817	9,618

Of the total costs for raising funds in 2020, £3,742 were out of restricted funds.

7 Expenditure on charitable activities

	Note	Unrestricted funds General £	Restricted funds £	Total 2021 £	Total 2020 £
Research		-	-	-	10,093
Support for WS community		-	19,329	19,329	-
Conference costs		-	573	573	-
Allocated support costs	8	-	214	214	-
Governance costs	8	12,485	2,710	15,195	17,597
		12,485	22,826	35,311	27,690

Of the total costs for charitable activites in 2020, £8,165 were out of restricted funds.

8 Analysis of governance and support costs

Raising funds expenditure

Costs of generating donations and legacies

	Unrestricted General £	Restricted £	Total 2021 £	Total 2020 £
Governance costs	878	76	954	1,961

Support costs allocated to raising funds

	Governance costs £	Total 2021 £	Total 2020 £
Costs of generating donations and legacies	954	954	1,961

Governance costs

	Unrestricted funds General £	Restricted funds £	Total 2021 £	Total 2020 £
Independent examiner fees				
Examination of the financial statements	900	-	900	810
Professional fees	10,411	-	10,411	10,884
Other governance costs	1,174	2,710	3,884	5,903
	12,485	2,710	15,195	17,597

9 Net incoming/outgoing resources

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

	2021 £	2020 £
Depreciation of fixed assets	286	106

10 Staff costs

The aggregate payroll costs were as follows:

	2021	2020
	£	£
Staff costs during the year were:		
Wages and salaries	6,604	6,482
Social security costs	269	-
Pension costs	262	189
	7,135	6,671

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

	2021	2020
	No	No
Full time employees	1	1

Contributions to the employee pension schemes for the year totalled £262 (2020 - £189).

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

11 Independent examiner's remuneration

	2021	2020
	£	£
Other fees to examiners		
The examining of accounts of any associate of the charity	900	810

12 Taxation

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

13 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 March 2020	3,659	3,659
Additions	219	219
At 28 February 2021	3,878	3,878
Depreciation		
At 1 March 2020	3,256	3,256
Charge for the year	286	286
At 28 February 2021	3,542	3,542
Net book value		
At 28 February 2021	336	336
At 29 February 2020	403	403

14 Stock

	2021 £	2020 £
Stocks	1,235	456

15 Debtors

	2021 £	2020 £
Trade debtors	10	-
Prepayments	243	315
Other debtors	673	673
	926	988

16 Creditors: amounts falling due within one year

	2021 £	2020 £
Trade creditors	706	692
Other taxation and social security	495	-
Accruals	900	772
	2,101	1,464

17 Funds

	Balance at 1 March 2020 £	Incoming resources £	Resources expended £	Transfers £	Balance at 28 February 2021 £
Unrestricted funds					
General					
General Funds	8,114	19,241	(19,180)	12,861	21,036
Designated					
Wolfram Syndrome Conference	11,421	-	-	(10,234)	1,187
Research Fund	36,821	29	-	(31,661)	5,189
	48,242	29	-	(41,895)	6,376
Total unrestricted funds	56,356	19,270	(19,180)	(29,034)	27,412
Restricted funds					
Wolfram Syndrome Conference	7,094	-	(573)	4,802	11,323
Research Fund	-	534	-	24,232	24,766
Chalk Cliff Trust	-	3,000	(3,000)	-	-
Breaking Down Barriers	4,740	-	(4,590)	150	300
The National Lottery Community Fund	9,965	-	(4,789)	(150)	5,026
Edward Gostling Foundation	-	5,500	(4,000)	-	1,500
NLCF/HMG Fund	-	9,950	(9,950)	-	-
Total restricted funds	21,799	18,984	(26,902)	29,034	42,915
Total funds	78,155	38,254	(46,082)	-	70,327

Notes to the Financial Statements for the Year Ended 28 February 2021

	Balance at 1 March 2019 £	Incoming resources £	Resources expended £	Transfers £	Balance at 29 February 2020 £
Unrestricted funds					
General					
General Funds	15,627	18,411	(27,067)	1,143	8,114
Designated					
Wolfram Syndrome Conference	10,894	-	527	-	11,421
Research Fund	24,362	19,503	(7,044)	-	36,821
	35,256	19,503	(6,517)	-	48,242
Total unrestricted funds	50,883	37,914	(33,584)	1,143	56,356
Restricted					
Wolfram Syndrome Conference	10,746	1,143	(4,795)	-	7,094
Awards for All	1	-	-	(1)	-
Research Fund	828	2,221	(3,049)	-	-
Chalk Cliff Trust	-	4,944	(3,802)	(1,142)	-
Breaking Down Barriers	-	5,000	(260)	-	4,740
The National Lottery Community Fund	-	9,965	-	-	9,965
Total restricted funds	11,575	23,273	(11,906)	(1,143)	21,799
Total funds	62,458	61,187	(45,490)	-	78,155

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 as well as to assist families/individuals in covering any travel/accommodation costs that are incurred by them for taking part in the 3 year clinical trial which started recruitment in January 2019, with regular visits to Birmingham Children's Hospital & Queen Elizabeth Hospital Birmingham. Historically this had been incorrectly allocated between designated, and restricted. A transfer has been made this year to correct this to ensure the closing balances are correct.

Chalk Cliff Trust Grant
Totalling £3,000 for enhanced front-line support to the WS community in response to COVID-19.

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

The National Lottery Community Fund
National Lottery Community Fund, Awards for All - £9,965 to be used for a Pilot project - Caregivers Well Being project.

Edward Gostling Foundation
Front-line support service for WS affected individuals, their Carers and wider families.

National Lottery Community Fund and HM Government's Coronavirus Community Support Fund
Used to fund the creation and postage of Wellbeing Packs in July and December to support the WS community during the first and second lockdowns. Items sent included sensory items to invoke feelings of wellbeing, treats and practical items to show that WSUK were still there to help them if required.

18 Analysis of net assets between funds

	Unrestricted funds General	Restricted funds	Total funds at 28 February 2021
	£	£	£
Intangible fixed assets	336	-	336
Current assets	29,177	42,915	72,092
Current liabilities	(2,101)	-	(2,101)
Total net assets	27,412	42,915	70,327

19 Analysis of net funds

	At 1 March 2020	Financing cash flows	At 28 February 2021
	£	£	£
Cash at bank and in hand	77,772	(7,841)	69,931
Net debt	77,772	(7,841)	69,931

20 Related party transactions

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

Tracy Lynch
(Related party of Trustee Paul Lynch)
Net wages - total: £6,029, project work - £2,113, reimbursed travel expenses - £160. At the balance sheet date the amount due to/from Tracy Lynch was £Nil (2020 - £Nil).

Gina Isherwood
(Related party of Trustee John Isherwood)
Consulting services - total: £17,000. At the balance sheet date the amount due to/from Gina Isherwood was £Nil (2020 - £Nil).

Paul Lynch
(Trustee)
Reimbursement of fuel, desk and working from home costs - total: £1,399. At the balance sheet date the amount due to/from Paul Lynch was £Nil (2020 - £Nil).