

Charity registration number: 1152445

# Wolfram Syndrome UK

Annual Report and Financial Statements

for the Year Ended 28 February 2019

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**

|                                    |   |
|------------------------------------|---|
| <b>Trustees</b>                    | Mr A Nye<br>Mr M Chandler<br>Prof T Barrett<br>Mr P Lynch<br>Mr D Lynch               |
| <b>Senior Management Team</b>      | T Lynch, Chief Executive  |
| <b>Principal Office</b>            | 9 Church Way<br>Tarring<br>Worthing<br>West Sussex<br>BN13 1HD                        |
| <b>Charity Registration Number</b> | 1152445   |
| <b>Independent Examiner</b>        | Hodson & Co<br>Wiston House<br>1 Wiston Avenue<br>Worthing<br>West Sussex<br>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 2019.

### **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 UK

## Trustees' Report

Wolfram Syndrome is a genetic disorder causing diabetes mellitus, optic atrophy and deafness. It affects children and adults and there is currently no known cure. There are currently around 85 diagnosed sufferers in the UK. This number is rising and expected to reach 120 due to improvements in the diagnosis of partial Wolfram. WSUK is the only specific national organisation/charity providing support to those affected and their families. WSUK is the only charity specifically raising money to finance research in to the causes and treatment of this illness. WSUK exists to meet these needs for this section of the public. Due to the rare and under-researched nature of this illness, diagnosis can currently take 3-6 years and can involve many varied 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 newsletter, website and annual conference will continue to increase levels of awareness, knowledge and understanding of this syndrome. These activities will benefit not only those currently affected but also future sufferers and their families, not least in sustaining an enhanced national focus on finding effective treatments and an eventual cure.

For those currently diagnosed and their families WSUK will maintain a voluntary register and distribute information about its aims, objectives and activities. WSUK will provide direct and practical benefit through information, advice and guidance but also through financial assistance in the form of grants where possible given at the discretion of the trustees. The care of WS children can often necessitate the purchase of specialist equipment and facilities for the home and where this cause's financial hardship WSUK will provide advice about financial support available and possible financial support from WSUK. This may be needed, for example, for the purchase of night monitoring equipment, CCTV, visual magnification and braille programmes, adaptations to rooms and specialist mobile phones. Many of these can be provided with financial support from local councils and other specialist organisations as well as WSUK.

A process through which any sufferer or their parent/carer, registered with WSUK, will be established to enable applications to be made for grant aid and this will be detailed on the website. The only restriction will be that there has been a diagnosis of WS and that the sufferer is a permanent UK resident and registered with WSUK. There is no charge made for registration with WSUK.

Further practical and emotional benefit is provided by WSUK to families living with WS in the form of an annual family conference, interim day clinics and family meetings. It is intended that these will be 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 when interest is shown.

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 will be raised through a number of dissemination activities organised through WSUK. This will include public and professional meetings at the Birmingham Children's Hospital clinic and the development of a family and professionals WS handbook. Where a specific need is identified, WSUK will respond through its own initiatives. For example, currently that would be by providing outreach workers within the Asian community with the information and training they need to recognise the symptoms of WS. From the professional forums initially organised at the Birmingham clinic as well as Internationally, WSUK will be able to identify potentially valuable research opportunities that it can support through its family network and financially. The WSUK website will also be used to further disseminate research results and publications.

All of these activities will be 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 trustees 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

### *Objectives, strategies and activities*

Fundraising events have included:

6th Annual Golf Day – best single fundraiser event to date  
Donations & Shaker collections  
Gift Aid payments  
Stamps & online shopping commission  
Sales of WSUK branded items including Christmas cards & calendar designed by a WS affected teenager  
Fundraising by families  
Facebook birthday donations  
80's Music concert  
London to Brighton Cycle ride – 3 riders  
Regular Monthly donations  
Worthing 10K – 4 runners  
50th Anniversary bike ride & celebration party  
Mini triathlon at Dorney Lake  
Sponsored Walk in memory of James Smith, a WS affected adult  
Dragon boat Festival stall  
Continued sales of a WS affected adult's autobiography as well as her newly published biography about her late brother, also affected by WS.

### *Public benefit*

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

The trustees confirm that they have complied with the requirements of section 4 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**

We had a third season with the charity caravan with a few WS families using it along with bookings through the holiday park, the decision was made by the Trustees towards the end of the season to sell the caravan back to the holiday park as the uptake wasn't sufficient from our families to warrant the costs we were paying out.

Our 7th Annual conference was held with a visiting Psychologist from Washington University Hospital, St Louis, USA who ran the psychology workshops & contributed to the combined WS workshops for those affected individuals. This combined workshop enables those affected by WS to ask questions freely to all the doctors that they don't want to say in front of a parent/partner or other loved one during a clinic visit. Following feedback we served a slightly simpler lunch & had this closer to all the presentation/workshop rooms. Around 92 people attended, with some new attendees once again. This was funded half by WSUK, through a donation by Penfold Verrall, & half by WellChild.

An update was given about the TREATWolfram clinical trial which has now had all checks carried out & clinical trial criteria approved; with the first paediatric affected recruits to be signed up at the January 2019 clinic. Affected adult recruitment is due to start in the summer of 2019 around the same time as the first of the 3 other countries taking part in this TREATWolfram trial. The UK aims to recruit 45 affected individuals, 23 children & 22 adults, out of a total of 70 recruits for the whole trial. WSUK made the first payment of £17,600 to cover the costs of travel & accommodation, where necessary, for UK participants for Year 1 of the trial. This first year payment will be higher than the subsequent 2 years as there are 7 visits to Birmingham with just 2 visits a year in years 2 & 3. The reimbursement of funds will be overseen by the University of Birmingham & the Clinical Trials Team. A statement will be sent to us at 6 months & 12 months each year so that we can see how much has been reimbursed.

# Wolfram Syndrome UK

## Trustees' Report

Some of our regular fundraising events continued. Our 6th golf day raised the largest amount yet for a single fundraiser event for research use with a total of £15,219, which was designated for research use with £15,000 being donated to research on a Zebrafish model looking at how WS affects the retinal ganglion cells, being carried out at Cambridge University Hospital. Our 80's night continues to be popular with tickets selling out 2 months before the event date. Shakers, regular monthly donations, stamps and the sale of charity Christmas cards continue to provide a regular source of income. Other fundraising income came from a 50th Anniversary sponsored bike ride, 3 cyclists taking part in a London to Brighton bike ride, 4 novice runners taking part in a Worthing's 10k run in June, a stall at the Dragon Boat Festival at Bewl Water in Kent, the uncle of an affected teenager taking part in a mini Triathlon at Dorney Lake & a team of 9 blind/vision impaired walkers taking part in a 21 mile walk from Whitby to Scarborough in memory of one of our members that passed away in May 2018. As well as Christmas cards for sale in 2018 we also had a calendar with the printed artwork of one of our VI teenagers. Next year we are looking into creating a book of poetry trying to involve as many of our WS members as possible.

WSUK received a £5000 donation from Penfold Verrall towards the funding of the annual family conference. In December 2018 the grant we received from Jeans for Genes ended. This was used to pay the wages of the one employee for the year. All of the other fundraising and donations throughout the year are generated by our own fundraising activities as well as other WS families & friends. Something that WSUK are looking to do is to diversify where our income stream comes from.

Our involvement continued with other Rare Disease organisations & International WS groups. On 28th February, which is Rare Disease Day, WSUK CEO Tracy Lynch was invited to present at Findacure's Drug Repurposing conference. She was asked to present about her family's journey from the forming of the charity to finding a potential treatment using a repurposed drug (TREATWolfram Trial). In March leaders of Rare Disease organisations were invited to attend the Genetic Disorders UK Leadership Symposium, which WSUK attended. This is the chance to hear from useful organisations, hear from medics and to network with likeminded individuals. Tracy Lynch also attended in June 2018 the International WS conference in Paris as representative of the charity along with the CEO's & founders of 4 other WS organisations from around the world. Here doctors and researchers gave updates on work they are currently carrying out & findings of work on projects that had been carried out over the last 18 months since the previous conference.

The quarterly newsletter continues to be sent out to everyone that has subscribed to it along with any trial updates. The newsletter has recently started to be shared in MP3 format for VI members and pictures have a text alternative for VI members that use screen reader.

WSUK were contacted by a few newly diagnosed families as well as families previously diagnosed that weren't ready to make that initial contact for support & advice over the course of 2018/19. These families were spoken to over the phone with helpful information then sent to them generally by email so they receive it straight away. They were given the information required to get a referral sent to the relevant clinic in Birmingham by their diagnosing doctor. WSUK informed the relevant Birmingham team to let them know that a referral was being sent so they could look out for it. WSUK continues to work as closely as possible with both teams at Birmingham Children's Hospital & the Queen Elizabeth Hospital.



# Wolfram Syndrome UK

## Trustees' Report

### **Financial review**

Total incoming resources for the year were £43,359 with expenditure of £53,893. Overall, there was a deficit for the year of £10,534. Unrestricted funds at 28 February 2019 were £50,883 and Restricted funds £11,575.

### ***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**

There are no material uncertainties about the charity's ability to continue.

### **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.



# Wolfram Syndrome UK

## Trustees' Report

### 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 14 October 2019 and signed on its behalf by:

.....

Mr A Nye  
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 14 October 2019 and signed on its behalf by:

.....  
Mr A Nye  
Trustee

## Wolfram Syndrome UK

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

I report on the accounts of the charity for the year ended 28 February 2019 which are set out on pages 10 to 25 .

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

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

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

- examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

#### **Basis of independent examiner's report**

My examination was carried out in accordance with the 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 you as 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 matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 386 of the Companies Act 2006; and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities

have not been met; or

(2) to which, in my opinion, attention should be drawn 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

14 October 2019

## Wolfram Syndrome UK

### Statement of Financial Activities for the Year Ended 28 February 2019 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

|                                    | Note | Unrestricted<br>funds<br>£ | Restricted<br>funds<br>£ | Total<br>2019<br>£ |
|------------------------------------|------|----------------------------|--------------------------|--------------------|
| <b>Income and Endowments from:</b> |      |                            |                          |                    |
| Donations and legacies             | 3    | 5,288                      | 6,601                    | 11,889             |
| Other trading activities           | 4    | 19,956                     | 7,488                    | 27,444             |
| Investment income                  | 5    | 93                         | -                        | 93                 |
| Other income                       | 6    | 3,933                      | -                        | 3,933              |
| Total Income                       |      | <u>29,270</u>              | <u>14,089</u>            | <u>43,359</u>      |
| <b>Expenditure on:</b>             |      |                            |                          |                    |
| Raising funds                      | 7    | (9,916)                    | (4,167)                  | (14,083)           |
| Charitable activities              | 8    | (19,481)                   | (20,329)                 | (39,810)           |
| Total Expenditure                  |      | <u>(29,397)</u>            | <u>(24,496)</u>          | <u>(53,893)</u>    |
| Net expenditure                    |      | (127)                      | (10,407)                 | (10,534)           |
| Transfers between funds            |      | (274)                      | 274                      | -                  |
| Net movement in funds              |      | (401)                      | (10,133)                 | (10,534)           |
| <b>Reconciliation of funds</b>     |      |                            |                          |                    |
| Total funds brought forward        |      | <u>51,284</u>              | <u>21,708</u>            | <u>72,992</u>      |
| Total funds carried forward        | 21   | <u>50,883</u>              | <u>11,575</u>            | <u>62,458</u>      |
|                                    | Note | Unrestricted<br>funds<br>£ | Restricted<br>funds<br>£ | Total<br>2018<br>£ |
| <b>Income and Endowments from:</b> |      |                            |                          |                    |
| Donations and legacies             | 3    | 5,328                      | 11,892                   | 17,220             |
| Other trading activities           | 4    | 24,021                     | 1,007                    | 25,028             |
| Investment income                  | 5    | 66                         | -                        | 66                 |
| Other income                       | 6    | 6,105                      | -                        | 6,105              |
| Total Income                       |      | <u>35,520</u>              | <u>12,899</u>            | <u>48,419</u>      |
| <b>Expenditure on:</b>             |      |                            |                          |                    |
| Raising funds                      | 7    | (23,417)                   | (833)                    | (24,250)           |
| Charitable activities              | 8    | (6,268)                    | -                        | (6,268)            |
| Total Expenditure                  |      | <u>(29,685)</u>            | <u>(833)</u>             | <u>(30,518)</u>    |
| Net income                         |      | <u>5,835</u>               | <u>12,066</u>            | <u>17,901</u>      |
| Net movement in funds              |      | 5,835                      | 12,066                   | 17,901             |
| <b>Reconciliation of funds</b>     |      |                            |                          |                    |
| Total funds brought forward        |      | <u>45,450</u>              | <u>9,643</u>             | <u>55,093</u>      |
| Total funds carried forward        | 21   | <u>51,285</u>              | <u>21,709</u>            | <u>72,994</u>      |

## **Wolfram Syndrome UK**

### **Statement of Financial Activities for the Year Ended 28 February 2019 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)**

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

The funds breakdown for 2018 is shown in note 21.

**Wolfram Syndrome UK**  
**(Registration number: CLUB)**  
**Balance Sheet as at 28 February 2019**

|  | Note | 2019<br>£      | 2018<br>£      |
|--|------|----------------|----------------|
| <b>Fixed assets</b>  |      |                |                |
| Tangible assets  | 15   | 10             | 12,304         |
| <b>Current assets</b>  |      |                |                |
| Stocks   | 16   | 566            | 805            |
| Debtors  | 17   | 1,538          | 6,337          |
| Cash at bank and in hand                                       |      | <u>61,394</u>  | <u>61,920</u>  |
|  |      | 63,498         | 69,062         |
| <b>Creditors: Amounts falling due within one year</b>          | 18   | <u>(1,050)</u> | <u>(2,870)</u> |
| <b>Net current assets</b>                                      |      | <u>62,448</u>  | <u>66,192</u>  |
| <b>Total assets less current liabilities</b>                   |      | 62,458         | 78,496         |
| <b>Creditors: Amounts falling due after more than one year</b> | 19   | <u>-</u>       | <u>(5,502)</u> |
| <b>Net assets</b>  |      | <u>62,458</u>  | <u>72,994</u>  |
| <b>Funds of the charity:</b>                                   |      |                |                |
| <b>Restricted funds</b>  |      | 11,575         | 21,709         |
| <b>Unrestricted income funds</b>                               |      |                |                |
| Unrestricted funds   |      | <u>50,883</u>  | <u>51,285</u>  |
| <b>Total funds</b>   | 21   | <u>62,458</u>  | <u>72,994</u>  |

For the financial year ending 28 February 2019 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 14 October 2019 and signed on their behalf by:

.....  
Mr A Nye  
Trustee

# Wolfram Syndrome UK

## Notes to the Financial Statements for the Year Ended 28 February 2019

### 1 Charity status

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

### 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) 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.

# Wolfram Syndrome UK

## Notes to the Financial Statements for the Year Ended 28 February 2019

### 2 Accounting policies (continued)

#### *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'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.



# Wolfram Syndrome UK

## Notes to the Financial Statements for the Year Ended 28 February 2019

### 2 Accounting policies (continued)

#### 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.

#### 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.

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 2 Accounting policies (continued)

##### Financial instruments

###### *Classification*

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

#### 3 Income from donations and legacies

|                                      | <b>Unrestricted<br/>funds</b> | <b>Restricted<br/>funds</b> | <b>Total<br/>2019</b> | <b>Total<br/>2018</b> |
|--------------------------------------|-------------------------------|-----------------------------|-----------------------|-----------------------|
|                                      | <b>General<br/>£</b>          | <b>£</b>                    | <b>£</b>              | <b>£</b>              |
| Donations and legacies;              |                               |                             |                       |                       |
| Donations from individuals           | 3,561                         | 6,601                       | 10,162                | 11,237                |
| Grants, including capital grants;    |                               |                             |                       |                       |
| Grants from other charities          | -                             | -                           | -                     | 5,000                 |
| Regular giving and capital donations | <u>1,727</u>                  | <u>-</u>                    | <u>1,727</u>          | <u>983</u>            |
|                                      | <u><u>5,288</u></u>           | <u><u>6,601</u></u>         | <u><u>11,889</u></u>  | <u><u>17,220</u></u>  |

#### 4 Income from other trading activities

|                             | <b>Unrestricted<br/>funds</b> | <b>Restricted<br/>funds</b> | <b>Total<br/>2019</b> | <b>Total<br/>2018</b> |
|-----------------------------|-------------------------------|-----------------------------|-----------------------|-----------------------|
|                             | <b>General<br/>£</b>          | <b>£</b>                    | <b>£</b>              | <b>£</b>              |
| Trading income;             |                               |                             |                       |                       |
| Sales of goods and services | 7,439                         | -                           | 7,439                 | 7,440                 |
| Events income;              |                               |                             |                       |                       |
| Other events income         | <u>12,517</u>                 | <u>7,488</u>                | <u>20,005</u>         | <u>17,588</u>         |
|                             | <u><u>19,956</u></u>          | <u><u>7,488</u></u>         | <u><u>27,444</u></u>  | <u><u>25,028</u></u>  |

#### 5 Investment income

|   | <b>Unrestricted<br/>funds</b> | <b>Total<br/>2019</b> | <b>Total<br/>2018</b> |
|---|-------------------------------|-----------------------|-----------------------|
|   | <b>General<br/>£</b>          | <b>£</b>              | <b>£</b>              |
| Interest receivable and similar income; |                               |                       |                       |
| Interest receivable on bank deposits    | <u>93</u>                     | <u>93</u>             | <u>66</u>             |

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 6 Other income

|               | <b>Unrestricted<br/>funds</b> | <b>Total<br/>2019</b> | <b>Total<br/>2018</b> |
|---------------|-------------------------------|-----------------------|-----------------------|
|               | <b>General<br/>£</b>          | <b>£</b>              | <b>£</b>              |
| Rental income | <u>3,933</u>                  | <u>3,933</u>          | <u>6,105</u>          |

#### 7 Expenditure on raising funds

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

|                         |             | <b>Unrestricted<br/>funds</b> | <b>Total<br/>2019</b> | <b>Total<br/>2018</b> |
|-------------------------|-------------|-------------------------------|-----------------------|-----------------------|
|                         | <b>Note</b> | <b>General<br/>£</b>          | <b>£</b>              | <b>£</b>              |
| Marketing and publicity |             | 148                           | 148                   | 1,406                 |
| Allocated support costs | 9           | <u>2,900</u>                  | <u>2,900</u>          | <u>3,236</u>          |
|                         |             | <u>3,048</u>                  | <u>3,048</u>          | <u>4,642</u>          |

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 7 Expenditure on raising funds (continued)

##### b) Costs of trading activities

|   |      | Unrestricted<br>funds |  | Restricted<br>funds | Total<br>2019 | Total<br>2018 |
|---|------|-----------------------|--|---------------------|---------------|---------------|
|   | Note | General<br>£          |  | £                   | £             | £             |
| Costs of goods sold                                   |      | (969)                 |  | -                   | (969)         | 7,930         |
| Depreciation, amortisation and other similar costs    |      | 4,594                 |  | -                   | 4,594         | 7,990         |
| Other direct costs of activities for generating funds |      | 3,243                 |  | 4,167               | 7,410         | 3,688         |
|   |      | <u>6,868</u>          |  | <u>4,167</u>        | <u>11,035</u> | <u>19,608</u> |

#### 8 Expenditure on charitable activities

|                  |      | Unrestricted<br>funds |  | Restricted<br>funds | Total<br>2019 | Total<br>2018 |
|------------------|------|-----------------------|--|---------------------|---------------|---------------|
|                  | Note | General<br>£          |  | £                   | £             | £             |
| Research         |      | 15,000                |  | 17,600              | 32,600        | -             |
| Governance costs | 9    | 4,481                 |  | 2,729               | 7,210         | 6,268         |
|                  |      | <u>19,481</u>         |  | <u>20,329</u>       | <u>39,810</u> | <u>6,268</u>  |

£19,481 (2018 - £6,268) of the above expenditure was attributable to unrestricted funds and £20,329 (2018 - £Nil) to restricted funds.

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 9 Analysis of governance and support costs

##### Raising funds expenditure

##### Costs of generating donations and legacies

|                  | <b>Unrestricted funds</b> | <b>Total 2019</b> | <b>Total 2018</b> |
|------------------|---------------------------|-------------------|-------------------|
|                  | <b>General</b>            | <b>£</b>          | <b>£</b>          |
|                  | <b>£</b>                  | <b>£</b>          | <b>£</b>          |
| Governance costs | 2,900                     | 2,900             | 3,236             |

##### Support costs allocated to raising funds

|  | <b>Governance costs</b> | <b>Total 2019</b> | <b>Total 2018</b> |
|--|-------------------------|-------------------|-------------------|
|  | <b>£</b>                | <b>£</b>          | <b>£</b>          |
| Costs of generating donations and legacies | 2,900                   | 2,900             | 3,236             |

##### Governance costs

|   | <b>Unrestricted funds</b> | <b>Restricted funds</b> | <b>Total 2019</b> | <b>Total 2018</b> |
|---|---------------------------|-------------------------|-------------------|-------------------|
|   | <b>General</b>            | <b>£</b>                | <b>£</b>          | <b>£</b>          |
|   | <b>£</b>                  | <b>£</b>                | <b>£</b>          | <b>£</b>          |
| Staff costs                             |                           |                         |                   |                   |
| Other staff costs                       | 1,183                     | -                       | 1,183             | 69                |
| Independent examiner fees               |                           |                         |                   |                   |
| Examination of the financial statements | 810                       | -                       | 810               | 690               |
| Legal fees                              | 1,025                     | -                       | 1,025             | -                 |
| Other governance costs                  | 1,463                     | 2,729                   | 4,192             | 5,509             |
|   | 4,481                     | 2,729                   | 7,210             | 6,268             |

#### 10 Net incoming/outgoing resources

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

|   | <b>2019</b> | <b>2018</b> |
|---|-------------|-------------|
|   | <b>£</b>    | <b>£</b>    |
| Loss on disposal of fixed assets held for the charity's own use | 4,573       | -           |
| Depreciation of fixed assets                                    | 21          | 7,990       |

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 11 Trustees remuneration and expenses

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

##### Mr A Nye

£Nil (2018: £44) of expenses were reimbursed to Mr A Nye during the year.

#### 12 Staff costs

The aggregate payroll costs were as follows:

|  | 2019<br>£    | 2018<br>£    |
|--|--------------|--------------|
| <b>Staff costs during the year were:</b> |              |              |
| Wages and salaries                       | 5,117        | 1,933        |
| Other staff costs                        | 1,183        | 69           |
|  | <u>6,300</u> | <u>2,002</u> |

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:

|                     | 2019<br>No | 2018<br>No |
|---------------------|------------|------------|
| Full time employees | <u>1</u>   | <u>1</u>   |

Contributions to the employee pension schemes for the year totalled £61 (2018 - £Nil).

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

#### 13 Independent examiner's remuneration

|   | 2019<br>£  | 2018<br>£  |
|---|------------|------------|
| Examination of the financial statements | <u>810</u> | <u>690</u> |

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 14 Taxation

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

#### 15 Tangible fixed assets

|                         | <b>Furniture and<br/>equipment<br/>£</b> | <b>Total<br/>£</b> |
|-------------------------|--|--------------------|
| <b>Cost</b>             |  |                    |
| At 1 March 2018         | 34,165                                   | 34,165             |
| Disposals               | <u>(31,005)</u>                          | <u>(31,005)</u>    |
| At 28 February 2019     | <u>3,160</u>                             | <u>3,160</u>       |
| <b>Depreciation</b>     |  |                    |
| At 1 March 2018         | 21,861                                   | 21,861             |
| Charge for the year     | 22                                       | 22                 |
| Eliminated on disposals | <u>(18,733)</u>                          | <u>(18,733)</u>    |
| At 28 February 2019     | <u>3,150</u>                             | <u>3,150</u>       |
| <b>Net book value</b>   |  |                    |
| At 28 February 2019     | <u>10</u>                                | <u>10</u>          |
| At 28 February 2018     | <u>12,304</u>                            | <u>12,304</u>      |

#### 16 Stock

|        | <b>2019<br/>£</b> | <b>2018<br/>£</b> |
|--------|-------------------|-------------------|
| Stocks | <u>566</u>        | <u>805</u>        |

#### 17 Debtors

|               | <b>2019<br/>£</b> | <b>2018<br/>£</b> |
|---------------|-------------------|-------------------|
| Trade debtors | -                 | 5,168             |
| Prepayments   | 865               | 496               |
| Other debtors | <u>673</u>        | <u>673</u>        |
|               | <u>1,538</u>      | <u>6,337</u>      |

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

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

|                                  | 2019<br>£    | 2018<br>£    |
|----------------------------------|--------------|--------------|
| Trade creditors                  | 310          | 275          |
| Hire purchase and finance leases | -            | 1,907        |
| Other creditors                  | (10)         | (2)          |
| Accruals                         | 750          | 690          |
|                                  | <u>1,050</u> | <u>2,870</u> |

#### 19 Creditors: amounts falling due after one year

|                                  | 2019<br>£ | 2018<br>£    |
|----------------------------------|-----------|--------------|
| Hire purchase and finance leases | <u>-</u>  | <u>5,502</u> |

#### 20 Obligations under leases and hire purchase contracts

The total value of future minimum lease payments was as follows:

##### [Repayable under finance leases and hire purchase contracts](#)

|                      | 2019<br>£ | 2018<br>£      |
|----------------------|-----------|----------------|
| Within one year      | -         | (1,907)        |
| In two to five years | <u>-</u>  | <u>(5,502)</u> |
|                      | <u>-</u>  | <u>(7,409)</u> |



## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 21 Funds

|                                 | Balance at 1<br>March 2018<br>£          | Incoming<br>resources<br>£          | Resources<br>expended<br>£          | Transfers<br>£         | Balance at<br>28<br>February<br>2019<br>£            |
|---------------------------------|--|-------------------------------------|-------------------------------------|------------------------|--|
| <b>Unrestricted funds</b>       |  |                                     |                                     |                        |  |
| <i>General</i>                  |  |                                     |                                     |                        |  |
| General Funds                   | 16,355                                   | 29,270                              | (14,399)                            | (15,600)               | 15,626   |
| <i>Designated</i>               |  |                                     |                                     |                        |  |
| Wolfram Sundrome Conference     | 10,787                                   | -                                   | -                                   | 107                    | 10,894   |
| Research Fund                   | 24,143                                   | -                                   | (15,000)                            | 15,219                 | 24,362   |
|                                 | <u>34,930</u>                            | <u>-</u>                            | <u>(15,000)</u>                     | <u>15,326</u>          | <u>35,256</u>  |
| <b>Total Unrestricted funds</b> | <u>51,285</u>                            | <u>29,270</u>                       | <u>(29,399)</u>                     | <u>(274)</u>           | <u>50,882</u>  |
| <b>Restricted funds</b>         |  |                                     |                                     |                        |  |
| Wolfram Syndrome Conference     | 8,389                                    | 5,087                               | (2,729)                             | -                      | 10,747   |
| Rewards for All                 | 19                                       | -                                   | -                                   | (18)                   | 1  |
| Research Fund                   | 9,134                                    | 9,002                               | (17,600)                            | 292                    | 828  |
| Salary Grant                    | 4,167                                    | -                                   | (4,167)                             | -                      | -  |
| <b>Total restricted funds</b>   | <u>21,709</u>                            | <u>14,089</u>                       | <u>(24,496)</u>                     | <u>274</u>             | <u>11,576</u>  |
| <b>Total funds</b>              | <u>72,994</u>                            | <u>43,359</u>                       | <u>(53,895)</u>                     | <u>-</u>               | <u>62,458</u>  |
|                                 | <b>Balance at 1<br/>March 2017<br/>£</b> | <b>Incoming<br/>resources<br/>£</b> | <b>Resources<br/>expended<br/>£</b> | <b>Transfers<br/>£</b> | <b>Balance at<br/>28<br/>February<br/>2018<br/>£</b> |
| <b>Unrestricted funds</b>       |  |                                     |                                     |                        |  |
| <i>General</i>                  |  |                                     |                                     |                        |  |
| General Funds                   | 27,299                                   | 35,520                              | (25,864)                            | (20,600)               | 16,355   |
| <i>Designated</i>               |  |                                     |                                     |                        |  |
| Wolfram Sundrome Conference     | 2,608                                    | -                                   | (3,821)                             | 12,000                 | 10,787   |
| Research Fund                   | 15,543                                   | -                                   | -                                   | 8,600                  | 24,143   |
|                                 | <u>18,151</u>                            | <u>-</u>                            | <u>(3,821)</u>                      | <u>20,600</u>          | <u>34,930</u>  |
| <b>Total unrestricted funds</b> | <u>45,450</u>                            | <u>35,520</u>                       | <u>(29,685)</u>                     | <u>-</u>               | <u>51,285</u>  |

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 21 Funds (continued)

|                               | Balance at 1<br>March 2017<br>£ | Incoming<br>resources<br>£ | Resources<br>expended<br>£ | Transfers<br>£ | Balance at<br>28<br>February<br>2018<br>£ |
|-------------------------------|---------------------------------|----------------------------|----------------------------|----------------|---|
| <b>Restricted funds</b>       |                                 |                            |                            |                |   |
| Wolfram Syndrome Conference   | 3,180                           | 5,209                      | -                          | -              | 8,389                                     |
| Rewards for All               | 19                              | -                          | -                          | -              | 19  |
| Research Fund                 | 6,444                           | 2,690                      | -                          | -              | 9,134                                     |
| Salary Grant                  | -                               | 5,000                      | (833)                      | -              | 4,167                                     |
| <b>Total restricted funds</b> | <u>9,643</u>                    | <u>12,899</u>              | <u>(833)</u>               | <u>-</u>       | <u>21,709</u>                             |
| <b>Total funds</b>            | <u>55,093</u>                   | <u>48,419</u>              | <u>(30,518)</u>            | <u>-</u>       | <u>72,994</u>                             |

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

**Wolfram Syndrome Conference**  
Income and costs towards the annual conferences.

**Awards for All**  
A grant received from the Big Lottery Awards for All programme for help with printing literature, a handbook for families and individuals and some medical wristbands.

**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 late 2017, with regular visits to Birmingham Children's Hospital.

**Salary Grant**  
Jeans for Genes awarded a grant of £5,000 for salaries during last year. This has been fully utilised by the end of this year.

#### 22 Analysis of net assets between funds

|                         | Unrestricted<br>funds<br>General<br>£ | Total funds<br>£ |
|-------------------------|---------------------------------------|------------------|
| Tangible fixed assets   | 10                                    | 10               |
| Current assets          | 63,498                                | 63,498           |
| Current liabilities     | (1,050)                               | (1,050)          |
| <b>Total net assets</b> | <u>62,458</u>                         | <u>62,458</u>    |

## Wolfram Syndrome UK

### Notes to the Financial Statements for the Year Ended 28 February 2019

#### 23 Analysis of net funds

|  | At 1 March<br>2018<br>£ | Cash flow<br>£ | At 28 February<br>2019<br>£ |
|--|-------------------------|----------------|-----------------------------|
| Cash at bank and in hand                   | 61,920                  | (526)          | 61,394                      |
| Finance leases and hire purchase contracts | (7,409)                 | 7,409          | -                           |
| Net debt                                   | <u>54,511</u>           | <u>6,883</u>   | <u>61,394</u>               |

#### 24 Related party transactions

There were no related party transactions in the year.