

WOLFRAM SYNDROME UK
ACCOUNTS
for the period ended
28 February 2015

Charity Number 1152445

HODSON & CO.
Chartered Accountants
Wiston House
1 Wiston Avenue
Worthing
West Sussex BN14 7QL

WOLFRAM SYNDROME UK

MEMBERS OF THE BOARD AND PROFESSIONAL ADVISERS

Registered charity name Wolfram Syndrome UK

Charity number 1152445

Trustees
Mr M Chandler
Mrs S Hawkins
Mr A Nye
Mr P Lynch
Mr D Lynch
Prof T Barrett

Independent examiner
M J Hodson FCA
Wiston House
1 Wiston Avenue
Worthing
West Sussex BN14 7QL

Bankers
Barclays
Leicester
LE87 2BB

WOLFRAM SYNDROME UK

TRUSTEES' ANNUAL REPORT

year ended 28 February 2015

The trustees present their report and the unaudited accounts of the charity for the year ended 28 February 2015.

REFERENCE AND ADMINISTRATIVE DETAILS

Reference and administrative details are shown in the schedule of members of the board and professional advisers on page 1 of the accounts.

THE TRUSTEES

The trustees who served the charity during the period were as follows:

Mr M Chandler
Mrs S Hawkins
Mr A Nye
Mr P Lynch
Mr D Lynch
Prof T Barrett

Mrs T Lynch (Retired 31 July 2014)
Miss A Hawkins (Retired 16 November 2014)

Mrs S Hawkins retired as a member of the committee on 16 April 2015.

STRUCTURE, GOVERNANCE AND MANAGEMENT

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.

Organisation

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.

Trustees

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

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

WOLFRAM SYNDROME UK

TRUSTEES' ANNUAL REPORT *(continued)*

year ended 28 February 2015

Trustee Induction and Training

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.

OBJECTIVES AND ACTIVITIES

Objectives

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

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 100 diagnosed sufferers in the UK. This number is rising and expected to reach 150 soon due to improvements in the diagnosis of partial Wolfram. There is no national organisation or charity providing support to sufferers or their families. Nor is there any charity specifically raising money to finance research in to the causes and treatment of this illness. WSUK will exist to meet these needs for this section of the public. 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 will raise funds to help finance further research and through its newsletter, website and annual conference will increase levels of awareness, knowledge and understanding of this illness. These activities will benefit not only current sufferers but also future sufferers and their families, not least in sustaining an enhanced national focus on finding effective treatments and an eventual cure.

WOLFRAM SYNDROME UK

TRUSTEES' ANNUAL REPORT *(continued)*

year ended 28 February 2015

For current sufferers 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 given at the discretion of the trustees. The care of WS children necessitates the purchase of specialist equipment and facilities for the home and where this cause's financial hardship WSUK will provide financial support. This may be needed, for example, for the purchase of night monitoring equipment, CCTV, visual magnification and braille programs, adaptations to rooms and specialist mobile phones.

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 will be no charge made for registration with WSUK. Further practical and emotional benefit will be 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 organise "take a break" opportunities for parents and carers at an affordable cost.

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 south 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 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.

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.

WOLFRAM SYNDROME UK

TRUSTEES' ANNUAL REPORT *(continued)*

year ended 28 February 2015

Activities

The charity organised several fundraising activities throughout the year. These included a golf day with raffle and auction; shakers in some local public houses and shops; shakers given out to other families to place in similar places; loose change boxes given out to families to share amongst other family members and friends; selling of charity Christmas cards and wristbands; coffee mornings and fundraiser days including a couple of supermarkets; two affected adults both did sponsored Sky Dives; an 'A Night at the 80's' concert with auction; people running half and full marathons; a 100 mile sponsored walk across the South Downs; a dress down day organised by a family in Malta at their affected son's school; a couple of families having stalls at local fairs; a local dance school donating the proceeds from their raffle; Brighton Gay Men's Chorus holding a collection at the end of one of their shows. Funds also came in via online donations and commission from an online shopping portal. An awareness campaign was organised in September delivering 400 medical information packs to 16 departments in 25 main children's hospitals around the UK. This raised funds as well as awareness amongst the medical profession. The annual conference was held for a third year co-organised with WellChild.

ACHIEVEMENTS AND PERFORMANCE

The charity performed well in its first year (9 months) and the number of people attending the 3rd annual conference increased from 79 to 92, including a research doctor from Washington University USA and a parent who is also CEO of a Trust Foundation also in USA, which was a great improvement and has spurred many more families and individuals on to fundraising for the charity for 2015/16. Awareness about Wolfram Syndrome is increasing locally to where events are being held and shakers being placed. A grant was received from the Big Lottery Awards for All programme for £4981.50 to help with printing of literature, a handbook for families and individuals whether newly or long term diagnosed and some medical wristbands. The charity has paid for information to be included within 'The GP Practice Managers Information Pack' which is delivered twice a year to 10,000 GP practices around the UK.

FINANCIAL REVIEW

Total incoming resources for the year were £52,134 with expenditure of £16,127. Overall, there was a surplus for the year of £36,007. Unrestricted funds at 28 February 2015 were £39,426.

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.

Risk Management

The trustees actively review the major risks that the charity faces on a regular basis and believe that maintaining reserves at current levels, combined with the annual review of the controls over key financial systems, will provide sufficient resources in the event of adverse conditions. The trustees have also examined other operational and business risks faced by the charity and confirm that they have established systems to mitigate the significant risks.

WOLFRAM SYNDROME UK

TRUSTEES' ANNUAL REPORT *(continued)*

year ended 28 February 2015


Investment Policy and Returns

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.

PLANS FOR FUTURE PERIODS

The charity will continue to develop and expand its operations. More families and people affected with WS are getting involved in fundraising activities for the charity. Donations are coming in from an online shopping portal, when people purchase from stores via this site. The charity will be applying for grants to help fund upcoming and future conferences; to fund running costs such as salaries etc; and to help with the purchase and running of a static caravan holiday home for families and individuals affected by Wolfram Syndrome at little or no cost to themselves. This will also be rented out when not used by the families to help fund the day to day running costs. WSUK will also offer the caravan for rent to families affected by Alstrom Syndrome and Bardet Biedl Syndrome (both similar to WS).

Signed on behalf of the trustees


.....
23/7/15

Mr D Lynch
Trustee

WOLFRAM SYNDROME UK

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF WOLFRAM SYNDROME UK

year ended 28 February 2015

I report on the accounts of the charity for the year ended 28 February 2015 which are set out on pages 9 to 16.

RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND EXAMINER

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

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 130 of the 2011 Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

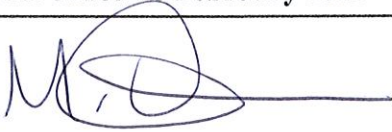
have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

WOLFRAM SYNDROME UK

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF WOLFRAM
SYNDROME UK** *(continued)*

year ended 28 February 2015



M J Hodson FCA
Independent examiner

Wiston House
1 Wiston Avenue
Worthing
West Sussex BN14 7QL

23/07/15

WOLFRAM SYNDROME UK

STATEMENT OF FINANCIAL ACTIVITIES

year ended 28 February 2015

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds Year to 28 Feb 15 £	Total Funds Period from 17 Jun 13 to 28 Feb 14 £
INCOMING RESOURCES					
Incoming resources from generating funds:					
Voluntary income	2	12,358	9,982	22,340	13,304
Activities for generating funds	3	29,794	—	29,794	6,705
TOTAL INCOMING RESOURCES		<u>42,152</u>	<u>9,982</u>	<u>52,134</u>	<u>20,009</u>
RESOURCES EXPENDED					
Costs of generating funds:					
Fundraising trading: cost of goods sold and other costs	4	(11,580)	—	(11,580)	(4,446)
Charitable activities	5/6	(835)	(3,000)	(3,835)	(4,970)
Governance costs	7	(712)	—	(712)	(192)
TOTAL RESOURCES EXPENDED		<u>(13,127)</u>	<u>(3,000)</u>	<u>(16,127)</u>	<u>(9,608)</u>
NET INCOMING RESOURCES FOR THE YEAR	8	29,025	6,982	36,007	10,401
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>10,401</u>	—	<u>10,401</u>	—
TOTAL FUNDS CARRIED FORWARD		<u>39,426</u>	<u>6,982</u>	<u>46,408</u>	<u>10,401</u>

The Statement of Financial Activities includes all gains and losses in the year and therefore a statement of total recognised gains and losses has not been prepared.

All of the above amounts relate to continuing activities.

The notes on pages 11 to 16 form part of these accounts.

WOLFRAM SYNDROME UK

BALANCE SHEET

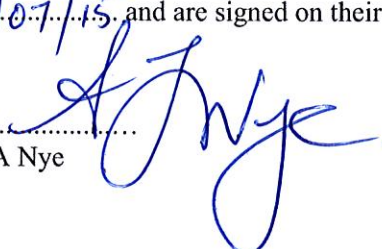
28 February 2015

	Note	£	2015 £	2014 £
FIXED ASSETS				
Tangible assets	11		2,450	1,074
CURRENT ASSETS				
Stocks	12	1,069		403
Debtors	13	1,587		1,177
Cash at bank and in hand		41,568		8,266
		<u>44,224</u>		<u>9,846</u>
CREDITORS: Amounts falling due within one year	14	<u>(265)</u>		<u>(519)</u>
NET CURRENT ASSETS			43,959	9,327
TOTAL ASSETS LESS CURRENT LIABILITIES			<u>46,409</u>	<u>10,401</u>
NET ASSETS			<u>46,409</u>	<u>10,401</u>
FUNDS				
Restricted income funds	15		6,982	–
Unrestricted income funds	16		39,427	10,401
TOTAL FUNDS			<u>46,409</u>	<u>10,401</u>

These accounts have been prepared in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008).

These accounts were approved by the members of the committee and authorised for issue on the 23/07/15 and are signed on their behalf by:

.....
Mr A Nye



The notes on pages 11 to 16 form part of these accounts.

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

year ended 28 February 2015

1. ACCOUNTING POLICIES

Basis of accounting

The accounts have been prepared under the historical cost convention and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008), and the requirements of the Statement of Recommended Practice 'Accounting and Reporting by Charities' issued in March 2005 (SORP 2005).

Fixed assets

All fixed assets are initially recorded at cost.

Depreciation

Depreciation is calculated so as to write off the cost of an asset, less its estimated residual value, over the useful economic life of that asset as follows:

Equipment - over 5 years

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

2. VOLUNTARY INCOME

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
Donations				
Donations	9,707	–	9,707	4,955
Donations - non gift aid	250	–	250	2,716
Gift aid payments received	2,401	–	2,401	8
Penfold Verrall	–	5,000	5,000	–
Gifts				
Gifts	–	–	–	655
Grants receivable				
Genetic Disorders UK	–	–	–	4,970
Awards for All	–	4,982	4,982	–
	<u>12,358</u>	<u>9,982</u>	<u>22,340</u>	<u>13,304</u>

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

year ended 28 February 2015

3. INCOMING RESOURCES FROM ACTIVITIES FOR GENERATING FUNDS

	Unrestricted Funds	Total Funds 2015	Total Funds 2014
	£	£	£
Other activities for generating funds - Charity Shop	5,263	5,263	970
Other activities for generating funds - Fundraising	24,531	24,531	5,735
	<u>29,794</u>	<u>29,794</u>	<u>6,705</u>

4. FUNDRAISING TRADING: COST OF GOODS SOLD AND OTHER COSTS

	Unrestricted Funds	Total Funds 2015	Total Funds 2014
	£	£	£
Fundraising	6,456	6,456	2,886
Support costs	5,124	5,124	1,560
	<u>11,580</u>	<u>11,580</u>	<u>4,446</u>

5. COSTS OF CHARITABLE ACTIVITIES BY FUND TYPE

	Unrestricted Funds	Restricted Funds	Total Funds 2015	Total Funds 2014
	£	£	£	£
Wolfram Syndrome Conference	<u>835</u>	<u>3,000</u>	<u>3,835</u>	<u>4,970</u>

6. COSTS OF CHARITABLE ACTIVITIES BY ACTIVITY TYPE

	Activities undertaken directly	Total Funds 2015	Total Funds 2014
	£	£	£
Wolfram Syndrome Conference	<u>3,835</u>	<u>3,835</u>	<u>4,970</u>

7. GOVERNANCE COSTS

	Unrestricted Funds	Total Funds 2015	Total Funds 2014
	£	£	£
Accountancy fees	250	250	—
Legal fees	400	400	—
Interest payable	42	42	—
Other financial costs	4	4	9
Other governance costs	16	16	183
	<u>712</u>	<u>712</u>	<u>192</u>

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

year ended 28 February 2015

8. NET INCOMING RESOURCES FOR THE YEAR

This is stated after charging:

	Year to 28 Feb 15	Period from 17 Jun 13 to 28 Feb 14
	£	£
Depreciation	568	142
	<u>568</u>	<u>142</u>

9. FUND TRANSFERS

The charity designated £4,200 of unrestricted funds in respect of the Wolfram Syndrome Conference, £15,000 towards Research funding and £16,000 towards the purchase of a holiday home for use by WS families and individuals.

10. STAFF COSTS AND EMOLUMENTS

Total staff costs were as follows:

	Year to 28 Feb 15	Period from 17 Jun 13 to 28 Feb 14
	£	£
Wages and salaries	770	—
Social security costs	—	—
	<u>770</u>	<u>—</u>

Particulars of employees:

The average number of employees during the year, calculated on the basis of full-time equivalents, was as follows:

	Year to 28 Feb 15	Period from 17 Jun 13 to 28 Feb 14
	No	No
Number of administrative staff	1	—
	<u>1</u>	<u>—</u>

No employee received remuneration of more than £60,000 during the year (2014 - Nil).

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

year ended 28 February 2015

11. TANGIBLE FIXED ASSETS

	Equipment £
COST	
At 1 March 2014	1,216
Additions	1,944
At 28 February 2015	<u>3,160</u>
DEPRECIATION	
At 1 March 2014	142
Charge for the year	568
At 28 February 2015	<u>710</u>
NET BOOK VALUE	
At 28 February 2015	<u>2,450</u>
At 28 February 2014	<u>1,074</u>

12. STOCKS

	2015 £	2014 £
Stock	<u>1,069</u>	<u>403</u>

13. DEBTORS

	2015 £	2014 £
Trade debtors	1,500	1,177
Prepayments	87	—
	<u>1,587</u>	<u>1,177</u>

14. CREDITORS: Amounts falling due within one year

	2015 £	2014 £
Trade creditors	17	519
Accruals	248	—
	<u>265</u>	<u>519</u>

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

year ended 28 February 2015

15. RESTRICTED INCOME FUNDS

	Incoming resources £	Outgoing resources £	Balance at 28 Feb 2015 £
Wolfram Syndrome Conference	5,000	(3,000)	2,000
Awards for All	4,982	—	4,982
	<u>9,982</u>	<u>(3,000)</u>	<u>6,982</u>

Wolfram Syndrome Conference

Annual income and costs towards the 2014 and 2015 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.

16. UNRESTRICTED INCOME FUNDS

	Balance at 1 Mar 2014 £	Incoming resources £	Outgoing resources £	Transfers £	Balance at 28 Feb 2015 £
Wolfram Syndrome Conference	—	—	(835)	4,200	3,365
Research fund	—	—	—	15,000	15,000
Holiday home	—	—	—	16,000	16,000
General Funds	10,401	42,152	(12,291)	(35,200)	5,062
	<u>10,401</u>	<u>42,152</u>	<u>(13,126)</u>	<u>—</u>	<u>39,427</u>

The following funds have been designated:

£4,200 towards the 2016 Wolfram Syndrome Conference;

£15,000 for Research purposes;

£16,000 towards the purchase of a static caravan holiday home for use by WS families and individuals.

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

year ended 28 February 2015

17. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Tangible fixed assets £	Net current assets £	Total £
Restricted Income Funds:			
Wolfram Syndrome Conference	–	2,000	2,000
Awards for All	–	4,982	4,982
	<u>–</u>	<u>6,982</u>	<u>6,982</u>
Unrestricted Income Funds:			
Designated Funds	–	34,365	34,365
General Funds	2,450	2,612	5,062
	<u>2,450</u>	<u>36,977</u>	<u>39,427</u>
Total Funds	<u>2,450</u>	<u>43,959</u>	<u>46,409</u>

18. RELATED PARTY TRANSACTIONS

The following trustees received travel, subsistence and accommodation costs:

Mr P Lynch £85 for accommodation;

Mr A Nye £178 for accommodation, drinks for WSUK guests and fuel for collecting guest speakers for the conference;

Mr M Chandler £150 for accommodation (including £75 for 2013 and £75 for 2014).