WOLFRAM SYNDROME UK ACCOUNTS for the period ended 29 February 2016

Charity Number 1152445

HODSON & CO.

Chartered Accountants
Wiston House
1 Wiston Avenue
Worthing
West Sussex BN14 7QL

MEMBERS OF THE BOARD AND PROFESSIONAL ADVISERS

Registered charity name

Wolfram Syndrome UK

Charity number

1152445

Trustees

Mr M Chandler 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

TRUSTEES' ANNUAL REPORT

year ended 29 February 2016

The trustees present their report and the unaudited accounts of the charity for the year ended 29 February 2016.

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 Mr A Nye Mr P Lynch Mr D Lynch Prof T Barrett

Mrs S Hawkins

(Retired 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.

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.

TRUSTEES' ANNUAL REPORT (continued)

year ended 29 February 2016

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.

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.

TRUSTEES' ANNUAL REPORT (continued)

year ended 29 February 2016

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.

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; selling of charity Christmas cards, charity logo items and wristbands; 25% of sales from a calendar produced by a local photographer; a team taking part in Worthing Birdman; a charity night at a local restaurant/café of live music, fun casino, raffle and auction; coffee mornings and fundraiser days including a couple of supermarkets; an 'A Fright Night at the 80's' concert with auction; people running half and full marathons; a couple of families having stalls at local fairs; a WS member selling handcrafted items; a family taking part in a sponsored Coast 2 Coast bike ride; a fundraiser day at a large local Utility company; a dance concert donating the ticket sale proceeds as well as a raffle; a cake sale in Malta organised by a family there; a "Different Shoe Day organised by office staff at National Express, Birmingham; donations from the funerals of 2 WS members; donation from the auction of a collection of toy cars belonging to a deceased WS member; sponsored bike ride around Devon. Funds also came in via online donations and commission from an online shopping portal, a sweet vending service and stamp collections. An awareness campaign was delivered to 10,000 GP practices around the UK. A new information handbook was produced for all patients especially newly diagnosed as well as people involved with their care and silicon usb wristbands for storing a person's medical information were given out. The annual conference was held for a fourth year co-organised with WellChild and with funding from a local company.

TRUSTEES' ANNUAL REPORT (continued)

year ended 29 February 2016

ACHIEVEMENTS AND PERFORMANCE

The charity had a quieter year with fewer events taking place. The number of people attending the 4th annual conference decreased from 92 to 73, partly due to the fact it was unfortunately held at the start of the Half Term break. Awareness about Wolfram Syndrome is increasing locally to where events are being held and shakers being placed. A grant received from the Big Lottery Awards for All programme for £4981.50 was used to print general leaflets to hand out, a handbook for families and individuals whether newly or long term diagnosed, to produce information sent out to 10,000 GP practices in the UK and some usb medical wristbands.

FINANCIAL REVIEW

Total incoming resources for the year were £26,402 with expenditure of £27,261. Overall, there was a small deficit for the year of £859. Unrestricted funds at 29 February 2016 were £36,922 and Restricted funds £8,628.

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.

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, commission from a sweet vending machine, stamp collections and a few regular monthly donors. The charity will be promoting the suggestion of regular donations. 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 a heavily discounted price. 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) at a discounted price.

TRUSTEES' ANNUAL REPORT (continued)

year ended 29 February 2016

Signed on behalf of the trustees

Mr D Lynch Trustee

D.) Solo6/2016

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

year ended 29 February 2016

I report on the accounts of the charity for the year ended 29 February 2016 which are set out on pages 9 to 17

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.

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

year ended 29 February 2016

M J Hodson FCA Independent examiner

Wiston House 1 Wiston Avenue Worthing West Sussex BN14 7QL

30/06/2016

STATEMENT OF FINANCIAL ACTIVITIES

year ended 29 February 2016

INCOME AND	Note	Unrestricted Funds	Restricted Funds	Total Funds 2016 £	Total Funds 2015 £
ENDOWMENTS Donations and legacies Other trading activities Investment income	2 3 4	1,729 18,534 74	2,140 3,925	3,869 22,459 74	22,340 29,794
TOTAL INCOME		20,337	6,065	26,402	52,134
EXPENDITURE Expenditure on raising fund Costs of other trading	ls:				-
activities Expenditure on charitable	5	(17,362)	(5,267)	(22,629)	(11,580)
activities	6/7	(1,734)	(2,898)	(4,632)	(4,548)
TOTAL EXPENDITURE		(19,096)	(8,165)	(27,261)	(16,128)
NET (OUTGOING)/INCOMIN G RESOURCES BEFORE TRANSFERS Transfer between funds		1,241 (3,746)	(2,100) 3,746	(859)	36,006
NET EXPENDITURE/INCOM AND NET MOVEMENT FUNDS FOR THE YEAR RECONCILIATION OF	IN	(2,505)	1,646	(859)	36,006
FUNDS Total funds brought forward	1	39,427	6,982	46,409	10,401
TOTAL FUNDS CARRIE FORWARD	ED	36,922	8,628	45,550	46,407

The Statement of financial activities includes all gains and losses in the year.

All of the above amounts relate to continuing activities.

The notes on pages 11 to 17 form part of these accounts.

BALANCE SHEET

29 February 2016

FIXED ASSETS Tangible assets	Note	£	2016 £	2015 £
Tangible assets	11		29,593	2,450
CURRENT ASSETS				
Stocks	12	841		1,069
Debtors	13	568		1,587
Cash at bank and in hand		32,347		41,568
CDEDITODS: Amounts falling due within one		33,756		44,224
CREDITORS: Amounts falling due within one year	14	(4,083)		(265)
NET CURRENT ASSETS			29,673	43,959
TOTAL ASSETS LESS CURRENT LIABILITIES	S		59,266	46,409
CREDITORS: Amounts falling due after more				
than one year	15		(13,715)	_
NET ASSETS			45,551	46,409
FUNDS OF THE CHARITY			,	
Restricted income funds	16		8,628	6,982
Unrestricted income funds	17		36,923	39,427
TOTAL CHARITY FUNDS			45,551	46,409

These accounts have been prepared in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015).

These accounts were approved by the members of the committee and authorised for issue on the 30.0616, and are signed on their behalf by:

The notes on pages 11 to 17 form part of these accounts.

NOTES TO THE ACCOUNTS

year ended 29 February 2016

1. ACCOUNTING POLICIES

Basis of accounting

The accounts have been prepared under the historical cost convention, as modified by the revaluation of certain fixed assets and investments measured at market value. The accounts have been prepared in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015), and the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015) (SORP 2015).

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 Plant & Machinery - 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.

Hire purchase agreements

Assets held under hire purchase agreements are capitalised and disclosed under tangible fixed assets at their fair value. The capital element of the future payments is treated as a liability and the interest is charged to the statement of financial activities on a straight line basis.

2. DONATIONS AND LEGACIES

	Unrestricted	Restricted	Total Funds
	Funds	Funds	2016
	£	£	£
Donations			
Donations	847	2,140	2,987
Donations - non gift aid			-
Gift aid payments received	882	-	882
Penfold Verrall		-	_
Grants receivable			
Awards for All		-	_
	GERMANIE	***************************************	SECURIOR SEC

NOTES TO THE ACCOUNTS

year ended 29 February 2016

		Unrestricted Funds £	Restricted Funds £	Total Funds 2015
	Donations	0.707		0.707
	Donations Donations Donations	9,707	_	9,707 250
	Donations - non gift aid	250 2,401	_	2,401
	Gift aid payments received Penfold Verrall	2,401	5,000	5,000
	Grants receivable		3,000	3,000
	Awards for All		4,982	4,982
	Awards for All	***************************************	4,902	4,962
		12,358	9,982	22,340
		E PERSONNEL SE SENSE SE S	BAS DESCRIPTION OF THE PROPERTY OF THE PROPERT	sealed the processing and process.
3.	OTHER TRADING ACTIVITIES			
		Unrestricted Funds	Funds	Total Funds 2016
	Other activities for generating funds - Charity Shop	£ 5,307	£	£ 5,307
	Other activities for generating funds - Fundraising	12,324	3,925	16,249
	Other activities for generating funds - Caravan	903	5,725	903
	a man and the general grant gr	-	2.025	
		18,534	3,925	22,459
		Unrestricted	Restricted	Total Funds
		Funds	Funds	2015
		£	£	£
	Other activities for generating funds - Charity Shop	5,263		5,263
	Other activities for generating funds - Fundraising	24,531	_	24,531
	Other activities for generating funds - Caravan	_	_	_
		29,794		29,794
		29,794	11020-05-783	29,794
4.	INVESTMENT INCOME			
	Unrestricted	Total Funds	Unrestricted	Total Funds
	Funds	2016	Funds	2015
	£	,	£	£
	Bank interest receivable 74	74	-	Record Control of Cont
5.	COSTS OF OTHER TRADING ACTIVITIES			
		Unrestricted	Restricted	Total Funds
		Funds	Funds	2016
		£	£	£
	Fundraising	11,206	5,267	16,473
	Fundraising - Caravan	2,713	-	2,713
	Support costs	3,443	****	3,443
		17,362	5,267	22,629
		Control of the Contro		

NOTES TO THE ACCOUNTS

year ended 29 February 2016

		Unrestricted	Restricted	Total Funds
		Funds	Funds	2015
		£	£	£
	Fundraising	6,456		6,456
	Fundraising - Caravan	-	-	
	Support costs	5,124	_	5,124
		11,580		11,580
			30 00 00 00 00 00 00 00 00 00 00 00 00 0	54.00 mm - 10.00 mm -
6.	COSTS OF CHARITABLE ACTIVITIES BY F	UND TYPE		
		Unrestricted	Restricted	Total Funds
		Funds	Funds	2016
		£	£	£
	Wolfram Syndrome Conference	150	2,898	3,048
	Support costs	1,584		1,583
		1,734	2,898	4,631
		 	and desired the state of the st	
		Unrestricted	Restricted	Total Funds
		Funds	Funds	2015
	W-16 C C	£	£	£
	Wolfram Syndrome Conference Support costs	835 712	3,000	3,835 713
	support costs			-
		1,547	3,000	4,548
7.	COSTS OF CHARITABLE ACTIVITIES BY A	CTIVITY TVP	E	
/·	COSTS OF CHARACTABLE ACTIVITIES BY		10 10	
		Activities		
			Total Funds	Total Funds
		directly £	2016 £	2015 £
	Wolfram Syndrome Conference	3,048	3,048	3,835
	Governance costs	-	1,583	713
		2.049	4,631	4,548
		3,048	4,031	4,346
8.	NET (OUTGOING)/INCOMING RESOURCES	FOR THE YEA	AR	
	This is stated after charging:			
	This is stated after charging.		2016	2015
			£	£
	Depreciation		3,862	568

NOTES TO THE ACCOUNTS

year ended 29 February 2016

9. FUND TRANSFERS

Transfers between unrestricted to restricted funds have been made during the year to cover balances on restricted funds.

10. STAFF COSTS AND EMOLUMENTS

FFT . 3	. 00					
Total	statt	COSTS	were	as	101	lows:

Total stall costs were as follows:		
	2016	2015
	£	£
Wages and salaries	1,320	770
Social security costs	_	
	1,320	770
	en e	

Particulars of employees:

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

	2016	2015
	No	No
Number of administrative staff	1	1
		THE REAL PROPERTY.

No employee received remuneration of more than £60,000 during the year (2015 - Nil).

11. TANGIBLE FIXED ASSETS

	Plant & Machinery £	Equipment £	Total £
COST At 1 March 2015	_	3,160	3,160
Additions	31,005	-	31,005
At 29 February 2016	31,005	3,160	34,165
DEPRECIATION At 1 March 2015		710	710
Charge for the year	3,230	632	3,862
At 29 February 2016	3,230	1,342	4,572
NET BOOK VALUE			00.500
At 29 February 2016	27,775	1,818	29,593
At 28 February 2015		2,450	2,450

NOTES TO THE ACCOUNTS

year ended 29 February 2016

11. TANGIBLE FIXED ASSETS (continued)

Hire purchase agreements

Included within the net book value of £29,593 is £27,775 (2015 - £Nil) relating to assets held under hire purchase agreements. The depreciation charged to the accounts in the year in respect of such assets amounted to £3,230 (2015 - £Nil).

12. STOCKS

2016	2015
Stock <u>£</u> 841	£ 1,069
13. DEBTORS	
2016	2015
£	£
Trade debtors 403	1,500
Prepayments 165	87
568	1,587
14. CREDITORS: Amounts falling due within one year	
2016	2015
£	£
Trade creditors 1,878	17
Hire purchase agreements 1,667	_
Accruals 538	248
4,083	265
15. CREDITORS: Amounts falling due after more than one year	
2016	2015
£	£
Hire purchase agreements 13,715	-

NOTES TO THE ACCOUNTS

year ended 29 February 2016

16. RESTRICTED INCOME FUNDS

	Balance at 1 Mar 2015 £	Income £	Expenditure £	Transfers £	Balance at 29 Feb 2016 £
Wolfram					
Syndrome					
Conference	2,000	456	(3,202)	3,746	3,000
Awards for All	4,982	_	(4,963)	-	19
Research fund	-	5,609	10 M		5,609
	6,982	6,065	(8,165)	3,746	8,628
	Control of the contro		The state of the s	-22-11-030	~

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.

17. UNRESTRICTED INCOME FUNDS

	Balance at 1 Mar 2015 £	Income £	Expenditure £	Transfers	Balance at 29 Feb 2016 £
Wolfram					
Syndrome					
Conference	3,365	_	-	(746)	2,619
Research fund	15,000	1,328	-	anne	16,328
Holiday home	16,000	_	_	(16,000)	
General Funds	5,062	19,009	(19,095)	13,000	17,976
	39,427	20,337	(19,095)	(3,746)	36,923

The following funds have been designated:

£1,328 for Research purposes;

NOTES TO THE ACCOUNTS

year ended 29 February 2016

18. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Tangible fixed assets	Net current assets	Long term liabilities	Total
Restricted Income Funds: Wolfram Syndrome Conference Awards for All Research fund	£	£	£	£
	North C	3,000	_	3,000
	-	19	-	19
	_	5,609	8 V 🔟	5,609
	-	0.600	*********	
		8,628	0.000	8,628
Unrestricted Income Funds:		Parameter in America		***************************************
Designated Funds General Funds		18,947	_	18,947
	29,593	2,098	(13,715)	17,976
	29,593	21,045	(13,715)	36,923
Total Funds	29,593	29,673	(13,715)	45,551
				200 00000000000000000000000000000000000

19. RELATED PARTY TRANSACTIONS

The following trustees received travel, subsistence and accommodation costs:

Mr P Lynch £59 for accommodation

Mr A Nye £87 for accommodation