

WOLFRAM SYNDROME UK
ACCOUNTS
for the period ended
28 February 2014

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

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

Bankers Barclays
Leicester
LE87 2BB

WOLFRAM SYNDROME UK

TRUSTEES' ANNUAL REPORT

period from 17 June 2013 to 28 February 2014

The trustees present their report and the unaudited accounts of the charity for the period from 17 June 2013 to 28 February 2014.

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:

Mrs T Lynch	(Appointed 17 June 2013)
Miss A Hawkins	(Appointed 17 June 2013)
Mr M Chandler	(Appointed 17 June 2013)
Mrs S Hawkins	(Appointed 17 June 2013)
Mr A Nye	(Appointed 17 June 2013)
Mr P Lynch	(Appointed 17 June 2013)
Mr D Lynch	(Appointed 17 June 2013)
Prof T Barrett	(Appointed 17 June 2013)

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 Mrs Tracy Lynch, trustee.

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)*

period from 17 June 2013 to 28 February 2014

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)*

period from 17 June 2013 to 28 February 2014

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)*

period from 17 June 2013 to 28 February 2014

Activities

The charity organised several fundraising activities throughout the year. These included a 20/20 cricket match with BBQ, raffle and auction; a golf day with raffle; 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. One family organised a team for a charity Dragon Boat race event with a tombola stand at the same event. The annual conference was held for a second year co-organised with WellChild.

A grant was received from Genetic Disorders UK to help finance the conference.

ACHIEVEMENTS AND PERFORMANCE

The charity performed well in its first year (9 months) and the number of people attending the 2nd annual conference increased from 41 to 79 which was a great improvement and has spurred many families on to fundraising for the charity for 2014/15. Awareness about Wolfram Syndrome is increasing locally to where events are being held and shakers being placed.

FINANCIAL REVIEW

Total incoming resources for the year were £20,009 with expenditure of £9,608. Overall, there was a surplus for the year of £10,401. Unrestricted funds at 28 February 2014 were £10,401.

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. A big awareness raising campaign is organised for September 2014 around the whole of the UK delivering detailed information packs to children's hospitals. More families and people affected with WS are getting involved in fundraising activities for the charity. An online shop has just been launched on the WSUK website and 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 us become self-sufficient for printing requirements for all literature, stickers etc.; to help fund upcoming and future conferences; to fund running costs such as salaries etc.

WOLFRAM SYNDROME UK

TRUSTEES' ANNUAL REPORT *(continued)*

period from 17 June 2013 to 28 February 2014

Signed on behalf of the trustees

Mrs T Lynch
Trustee

21 October 2014

WOLFRAM SYNDROME UK

STATEMENT OF FINANCIAL ACTIVITIES

period from 17 June 2013 to 28 February 2014

		Unrestricted Funds	Restricted Funds	Total Funds Period from 17 Jun 13 to 28 Feb 14
	Note	£	£	£
INCOMING RESOURCES				
Incoming resources from generating funds:				
Voluntary income	2	8,334	4,970	13,304
Activities for generating funds	3	6,705	–	6,705
TOTAL INCOMING RESOURCES		<u>15,039</u>	<u>4,970</u>	<u>20,009</u>
RESOURCES EXPENDED				
Costs of generating funds:				
Fundraising trading: cost of goods sold and other costs	4	(4,446)	–	(4,446)
Charitable activities	5/6	–	(4,970)	(4,970)
Governance costs	7	(192)	–	(192)
TOTAL RESOURCES EXPENDED		<u>(4,638)</u>	<u>(4,970)</u>	<u>(9,608)</u>
NET INCOMING RESOURCES FOR THE PERIOD	8	10,401	–	10,401
RECONCILIATION OF FUNDS				
Total funds brought forward		–	–	–
TOTAL FUNDS CARRIED FORWARD		<u>10,401</u>	<u>–</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 9 to 12 form part of these accounts.

WOLFRAM SYNDROME UK

BALANCE SHEET

28 February 2014

	Note	£	28 Feb 14 £
FIXED ASSETS			
Tangible assets	10		1,074
CURRENT ASSETS			
Stocks	11	403	
Debtors	12	1,177	
Cash at bank and in hand		8,266	
		<u>9,846</u>	
CREDITORS: Amounts falling due within one year	13	<u>(519)</u>	
NET CURRENT ASSETS			9,327
TOTAL ASSETS LESS CURRENT LIABILITIES			<u>10,401</u>
FUNDS			
Restricted income funds	14		–
Unrestricted income funds	15		10,401
TOTAL FUNDS			<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 21 October 2014 and are signed on their behalf by:

MRS T LYNCH

MR A NYE

The notes on pages 9 to 12 form part of these accounts.

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

period from 17 June 2013 to 28 February 2014

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 2014 £
Donations			
Donations	4,955	–	4,955
Donations - non gift aid	2,716	–	2,716
Gift aid payments received	8	–	8
Gifts			
Gifts	655	–	655
Grants receivable			
Genetic Disorders UK	–	4,970	4,970
	<u>8,334</u>	<u>4,970</u>	<u>13,304</u>

3. INCOMING RESOURCES FROM ACTIVITIES FOR GENERATING FUNDS

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

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

period from 17 June 2013 to 28 February 2014

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

	Unrestricted Funds	Total Funds 2014
	£	£
Fundraising trading	2,886	2,886
Support costs	1,560	1,560
	<u>4,446</u>	<u>4,446</u>

5. COSTS OF CHARITABLE ACTIVITIES BY FUND TYPE

	Restricted Funds	Total Funds 2014
	£	£
Wellchild conference	4,970	4,970
	<u>4,970</u>	<u>4,970</u>

6. COSTS OF CHARITABLE ACTIVITIES BY ACTIVITY TYPE

	Grant funding activities	Total Funds 2014
	£	£
Wellchild conference	4,970	4,970
	<u>4,970</u>	<u>4,970</u>

7. GOVERNANCE COSTS

	Unrestricted Funds	Total Funds 2014
	£	£
Other financial costs	9	9
Other governance costs	183	183
	<u>192</u>	<u>192</u>

8. NET INCOMING RESOURCES FOR THE PERIOD

This is stated after charging:

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

9. STAFF COSTS AND EMOLUMENTS

No salaries or wages have been paid to employees, including the members of the committee, during the period.

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

period from 17 June 2013 to 28 February 2014

10. TANGIBLE FIXED ASSETS

	Equipment £
COST	
Additions	1,216
At 28 February 2014	<u>1,216</u>
DEPRECIATION	
Charge for the period	142
At 28 February 2014	<u>142</u>
NET BOOK VALUE	
At 28 February 2014	<u>1,074</u>

11. STOCKS

	28 Feb 14 £
Stock	<u>403</u>

12. DEBTORS

	28 Feb 14 £
Trade debtors	<u>1,177</u>

13. CREDITORS: Amounts falling due within one year

	28 Feb 14 £
Trade creditors	<u>519</u>

14. RESTRICTED INCOME FUNDS

	Incoming resources £	Outgoing resources £	Balance at 28 Feb 2014 £
Wellchild conference	<u>4,970</u>	<u>(4,970)</u>	<u>–</u>

The charity received a grant of £4,970 from Genetic Disorders UK in respect of the Wolfram Syndrome Information and Support Day.

WOLFRAM SYNDROME UK

NOTES TO THE ACCOUNTS

period from 17 June 2013 to 28 February 2014

15. UNRESTRICTED INCOME FUNDS

	Incoming resources £	Outgoing resources £	Balance at 28 Feb 2014 £
General Funds	<u>15,039</u>	<u>(4,638)</u>	<u>10,401</u>

16. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Tangible fixed assets £	Net current assets £	Total £
Unrestricted Income Funds	<u>1,074</u>	<u>9,327</u>	<u>10,401</u>
Total Funds	<u>1,074</u>	<u>9,327</u>	<u>10,401</u>

17. RELATED PARTY TRANSACTIONS

The following trustees received travel, subsistence and accommodation costs:

P Lynch £67

T Lynch £59

A Nye £8