

SarcoidosisUK

Trustees' Report and Financial Statements Year ended: 31 December 2018

Charity no: 1063986

Reference and administrative information

Trustees

P Sinclair, Secretary (elected Chair of trustees, 18 July 2019)
H Shelford, Chair of Trustees (elected 18 July 2019)
J Cordner, Treasurer (elected 18 July 2019)
S Wilson (elected 18 July 2019)
E Gadimaliyev (elected 18 July 2019)
R Etienne (elected 18 July 2019)

Principal Office

5th Floor, Capital House, 42 Weston Street, London SE1 3QD

Charity Number: 1063986

Bankers

CAF Bank, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ

Report of the trustees for the year ended 31 December 2018

The trustees present their annual report and financial statements of the charity for the year ended 31st December 2018. The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the accounts, the Charities Act 2011 and the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Charities published on 16 July 2014.

Structure, governance and management

SarcoidosisUK is a registered charity, number 1063986, and is constituted under a trust deed dated 18 November 1996, as amended 29 May 1997 and 6th June 2014.

Trustee Appointment.

Trustees are appointed by member vote. All trustees are personally affected by sarcoidosis. The board of trustees regularly reviews the skills and experience of members to ensure that, as the legal and operational backbone of the charity, the board is as strong as possible.

Objectives and activities

SarcoidosisUK has four goals:

1. **Information:** We provide accurate and detailed information to people with sarcoidosis, their carers, healthcare professionals and anyone else personally or professionally affected by sarcoidosis.
2. **Support:** We provide emotional and confidential support for anyone affected by sarcoidosis in the UK.
3. **Research:** We raise funds and invests them into medical research focussed directly on finding a cure for sarcoidosis.
4. **Awareness:** We recognise the lack of understanding and awareness from both the medical profession and the general public regarding sarcoidosis. We aim to raise awareness through everything we do.

Achievements and performance

- **SarcoidosisUK Patient Council**

We've always known that we have an incredible group of supporters who show unrivalled knowledge about sarcoidosis and passion for the charity. This year we have set up a Patient Council for patients to get further involved with the charity, particularly with research and awareness projects. The board currently has 31 members and has already contributed to a number of important projects.

- **Clinical Board**

SarcoidosisUK has formed and developed great relationships with many sarcoidosis specialists from across the UK over the past few years. Many consultants have helped the charity, for instance in writing our Patient Information Leaflets. In spring 2019 we formed a Clinical Board to help with SarcoidosisUK's clinically related outputs and services. The Board is currently 9 members and has a first meeting in September 2019.

- **Specialist Patient Days**

Many patients have been calling for SarcoidosisUK to host patient conference days, particularly those who cannot reach our current support group locations and feel isolated. In June 2019 we held the first of these at the Royal Free – SarcoidosisUK Neurosarcoidosis Patient Day. Over 65 patients attended and hundreds watched via livestream as Dr Kidd,

Consultant Neurosarcoidosis Specialist, spoke about the condition.

- **We have recorded an amazing 2,200% increase in website traffic over the past year**
We now have around 20,000 unique visitors per month compared to an average of 8,000 per month a year ago. We think of every person who visits as someone we've helped so seeing this number go up so dramatically means a lot to us. We have invested in website security to ensure we can provide online support 100% of the time.
- **We've funded another major research project**
In 2018 we funded Dr Simon Hart at the University of Hull to analyse the effectiveness of the antibiotic Azithromycin in reducing mTOR activity in sarcoidosis patients. In addition we have conducted our own exciting research projects: digitalising the KSQ and conducting the SarcoidosisUK BIG Survey, a detailed collection of sarcoidosis patient demographic data. We've also continued our partnership with the British Lung Foundation and look forward to announcing the 2019 grant winner.
- **Our Support Services continue to go from strength to strength**
The SarcoidosisUK Nurse Helpline has now spoken to over 700 callers, we have 14 active Support Groups and have just accepted our 3,000th member to the SarcoidosisUK Facebook Group.
- **We've been continuing our national and international advocacy work**
We are represented on the European Respiratory Society (ERS) Patient Advisory Committee, an ERS Taskforce writing new sarcoidosis treatment guidelines and the ERS Patient Priorities project where he is leading a working group writing a checklist tool to help consultations. Jack is also sitting on the BTS Sarcoidosis Registry Steering Group, the WASOG FSR Centres of Excellence Committee and the NHS England Infliximab Commissioning Policy Working Group. Jo Whight, Helpline Nurse, is a patient representative on the British Thoracic Society (BTS) Sarcoidosis Statement taskforce.
- **Plans for next year**
We intend to build again on our success. To further enhance the information we give out, to build deeper partnerships within the medical community, provide even more support, improve awareness of this disease. And, of course, to fund another potentially ground-breaking piece of research towards a cure for sarcoidosis.

Financial review

The Charity has been almost entirely reliant on donations from the public. In 2018, voluntary income was £130,067 (2017 - £76,038), up 71%.

Just Giving has resulted in income of £51,298 (2017 - £39,582) against costs of £655 (2017 - £545) and was our largest source of income. In addition, personal donations resulted in income of £47,071. Donations 'in memory' produced income to the charity of £20,147.

Expenditure in 2018 has increased to £161,519 (2017 - £128,092), up 26%. The increase was mainly due to the increased costs we have invested in fundraising activities.

Reserves policy

The trustees aim to maintain free reserves in unrestricted funds at a level which equates to approximately six months of unrestricted charitable expenditure. The trustees consider that this level will provide sufficient funds to respond to applications for grants and ensure that there are sufficient funds available to cover support and governance costs.

Approved by the trustees on 21st October 2019 and signed on their behalf by:

A handwritten signature in blue ink, appearing to read 'Henry Shelford', with a long horizontal flourish extending to the right.

H Shelford

SarcoidosisUK
Registered Charity Number 1063986

Independent examiners report to the trustees of "SarcoidosisUK"

I report on the trustees report (pages 3 to 5) and the accounts of the association for the year ended 31st December 2018, which are set out on pages 7 to 13.

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 included 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 Charities 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.

Ray Haynes FCCA
Winter & Co
Chartered Association of Certified Accountants
47 Coleridge Way
Orpington
BR6 0UQ



24th October 2019

SarcoidosisUK

Statement of Financial Activities for the year ended 31 December 2018

	Notes	General Funds 2018 £	Total 2018 £	Total 2017 £
Incoming Resources				
Incoming resources from generated funds				
Donations	2	128,962	128,962	76,038
Charitable activities	3	1,105	1,105	-
Other	4	121	121	109
Total incoming resources		130,188	130,188	76,147
Resources expended				
Less: Expenditure on				
Raising funds	5	84,407	84,407	56,651
Charitable activities	6	77,112	77,112	71,441
Total expenditure		161,519	161,519	128,092
Net incoming /(expenditure)		(31,331)	(31,331)	(51,945)
Net movement in funds		(31,331)	(31,331)	(51,945)
Reconciliation of funds				
Total funds brought forward		161,617	161,617	213,562
Total funds carried forward		130,286	130,286	161,617

SarcoidosisUK

Balance Sheet as at 31 December 2018

	Notes	2018 £	2017 £
Fixed assets			
Office equipment	7	2,509	1,592
		<u>2,509</u>	<u>1,592</u>
Current Assets			
Debtors	8	1,244	493
Cash at bank and in hand		188,582	220,232
		<u>189,826</u>	<u>220,725</u>
Creditors: amounts falling due within one year	9	62,049	60,700
		<u>62,049</u>	<u>60,700</u>
Net Current Assets		<u>127,777</u>	<u>160,025</u>
Net Assets		<u>130,286</u>	<u>161,617</u>
The funds of the charity:			
Unrestricted funds			
General fund	10	126,676	158,007
Designated fund	10	3,610	3,610
Total funds		<u>130,286</u>	<u>161,617</u>

Notes to the accounts

1. Accounting Policies

(a) Basis of preparation

The financial statements have been prepared under the historic cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant notes. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic Of Ireland (FRS 102) issued on 16 July 2014 and the Charities Act 2011.

The charity constitutes a public benefit entity as defined by FRS102.

(b) Fund structure

The charity had up to 31 December 2014 a single unrestricted general fund. In 2015 it was decided that a designated fund of £180,000 be set up to fund research.

(c) Incoming resources

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received and the monetary value of incoming resources can be measured with sufficient reliability. Incoming resources comprise:

Direct giving	Cash donations and regular gifts are accounted for as received.
Events	Voluntary income arising from major events is recognised in the period in which the event takes place.
Gift Aid	Gift Aid is included based on amounts recoverable at the accounting date.
Legacies	Pecuniary legacies are recognised as receivable once probate has been granted and notification has been received. Residuary legacies are recognised as receivable once probate has been granted, provided that sufficient information has been received to enable valuation of the charity's entitlement.

(d) Resources expended

Liabilities are recognised as resources expended as soon as there is a legal or constructive obligation committing the charity to the expenditure. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category.

(e) Allocation of overhead and support costs

Where relevant, any support costs have been allocated to an appropriate charitable activity in 2018.

(f) Governance costs

Governance costs comprise all costs involving the public accountability of the charity and its compliance with regulation and good practice. These costs are detailed in note 6.

(g) Depreciation

Depreciation is provided at rates calculated to write off the assets over their estimated useful lives on the following basis:

- Computer and office equipment 25% net book value

2. Donations

	Unrestricted £	2018 Total £	2017 Total £
Corporate	521	521	1,399
In memoriam	20,147	20,147	9,131
Just Giving	51,298	51,298	39,582
Facebook	9,106	9,106	-
Grants	-	-	3,000
Virgin Money	469	469	8,039
Subscriptions	349	349	288
Individuals	47,071	47,071	14,599
	<u>128,962</u>	<u>128,962</u>	<u>76,038</u>

3. Charitable activities

	2018 Total £	2017 Total £
Merchandise sales	1,105	-
	<u>1,105</u>	<u>-</u>

4. Other income

	2018 Total £	2017 Total £
Interest on cash deposits	<u>121</u>	<u>109</u>

5. Resources Expended – Raising funds

	2018 Fundraising	2018 Total £	2017 Total £
Advertising	1,318	1,318	2,858
Accountancy		480	240
Bank charges		138	94
Conferences		1,072	-
Depreciation		627	410
Employer's NI		2,288	785
Fundraising	2,537	2,537	44
Insurance		1,469	1,183
Just Giving	655	655	545
Legal & professional fees		440	-
Literature		-	15
Meetings		894	87
Membership fees		-	59
Merchandise expenses	315	315	-
Office rental		10,800	7,100
Computer and IT expenditure	229	2,714	2,583
Pension costs		670	68
Postage		2,072	669
Office expenses		1,721	1,502
Staff costs	22,779	49,583	36,501
Stationery		1,209	111
Subsistence		33	72
Sundry		1,251	239
Surveys		50	-
Telephone		75	65
Training		466	985
Travel expenses		569	75
Website maintenance	961	961	360
	28,794	84,407	56,651

6. Resources Expended – Charitable activities

	Unrestricted £	2018 Total £	2017 Total £
Sponsorship	1,828	1,828	1,865
Research funded (designated fund)	60,194	60,194	59,982
Educational material	1,401	1,401	176
Nurse helpline	7,282	7,282	3,239
Support groups	6,407	6,407	6,179
	77,112	77,112	71,441

7. Tangible fixed assets

	Total £
Cost at 1 January 2018	2,188
Additions in year	1,544
Disposals in year	-
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Cost at 31 December 2018	3,732
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Depreciation at 1 January 2018	596
Charge in year	627
Disposals in year	-
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Depreciation at 31 December 2018	1,223
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Net book value at 1 January 2018	1,592
Net book value at 31 December 2018	2,509

8. Debtors

	2018 Total £	2017 Total £
Other debtors	1,244	493
	<hr/>	<hr/>
	1,244	493
	<hr/>	<hr/>

9. Creditors falling due within one year

	2018 Total £	2017 Total £
Trustees expenses outstanding	80	33
British Lung Foundation	-	59,982
Hull York Medical School	59,992	-
PAYE & NI	1,174	
Other creditors	803	685
	<hr/>	<hr/>
	62,049	60,700
	<hr/>	<hr/>

10. Summary of fund movements

	Fund balances brought forward £	Income £	Expenditure £	Transfers £	Fund balances carried forward £
General fund	158,007	130,188	(161,519)	-	126,676
Designated fund	3,610		-	-	3,610
Total funds	161,617	130,188	(161,519)	-	130,286

11. Related party transactions

The Charity currently sources some of its software on a subscription basis through a related party at a discounted price. The related party supplies the software at cost which totalled £144 for the year to 31 December 2018