

# SarcoidosisUK

## Trustees' Report and Financial Statements Year ended: 31 December 2019

Charity no: 1063986

## **Reference and administrative information**

### **Trustees**

P Sinclair, Secretary (elected 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**

214 China Works, 100 Black Prince Road, London SE1 7SJ

**Charity Number: 1063986**

### **Bankers**

CAF Bank, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ  
Co-operative Bank, 1 Balloon Street, Manchester M60 4EP

## **Report of the trustees for the year ended 31 December 2019**

The trustees present their annual report and financial statements of the charity for the year ended 31st December 2019. 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 October 2019.

## **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 6 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 invest 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 Support Services**  
The SarcoidosisUK Nurse Helpline continued to go from strength to strength and had answered over 1,000 calls by the end of 2019. The SarcoidosisUK Facebook group reached 3,482 members and we now have 21 active regional support groups.
- **We funded another major research project**  
SarcoidosisUK continues to fund research in partnership with the British Lung Foundation. In 2019 we committed £60,000 to a laboratory analysis of scarring in the lungs. The aim of the research is to understand scarring mechanisms and provide evidence for what treatment approaches may be effective. We have also conducted our own research projects, for example, the SarcoidosisUK BIG Survey, a detailed collection of sarcoidosis patient demographic data. This data will be used to help inform future research priorities.
- **Specialist Patient Days and Information Videos**  
In June 2019 we hosted the SarcoidosisUK Neurosarcoidosis Patient Day at the Royal Free Hospital in London. Over 65 patients attended and hundreds watched online as Dr Kidd, Consultant Neurosarcoidosis Specialist, spoke about the condition. We also created a number of information videos with experts Dr Athol Wells and Dr Desmond Kidd, which provide an in-depth explanation of complex and progressive sarcoidosis

and neurosarcoidosis.

- **Clinical Board**

In spring 2019 we formed a Clinical Board to help with SarcoidosisUK's clinically related outputs and services. There are currently 8 sarcoidosis specialists on the Board, which had its first meeting in September 2019.

- **Our online presence continued to grow**

In 2019 the SarcoidosisUK website recorded an average of over 35,000 unique visitors per month, compared to an average of around 20,000 per month in 2018. Our social media following has also grown significantly, allowing us to raise awareness and share our important work with a wider audience. Our Facebook page achieved 4,983 likes, compared to 3,554 in 2018.

- **Plans for next year**

SarcoidosisUK aims to increase fundraising and reach, in order to allow us to continue achieving our goals of funding research into a cure, offering support to people affected by sarcoidosis, providing high-quality information and raising awareness of the condition. 2020 has been an extremely challenging year, particularly for people with rare diseases. In response to the coronavirus pandemic, SarcoidosisUK has focussed on identifying and circulating specific advice for people with sarcoidosis. This has included creating a Coronavirus and Sarcoidosis FAQ and producing 7 live Q&A videos with specialists.

### **Legacy income**

We would like to express our gratitude for the generous legacy we received during the year. Legacies are an important source of funds for us and each one helps us to achieve our goals of helping others through the work we do. Without such generous donations, our charity would not be able to fund the research we do year after year or support the many sufferers out there who look to us for help. Thank you from all of us at SarcoidosisUK.

### **Financial review**

The Charity has been almost entirely reliant on donations from the public. In 2019, voluntary income was £209,368 (2018 - £130,067), up 61%. A grant of £7,000 was also received to assist with the costs of the SarcoidosisUK Nurse Helpline.

Direct donations from individuals resulted in income of £71,906 (2018 - £47,071) and were our largest source of funds. In addition, Just Giving resulted in income of £48,972 (2018 - £47,071) and Facebook donations produced income of £28,087 (2018 - £9,106). The charity also received a legacy of £27,000 during the year.

Expenditure in 2019 has increased to £176,169 (2018 - £161,519), up 9%. This was mainly due to an increase in fundraising expenses to £40,598 (2018 - £28,794)

**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 28<sup>th</sup> October 2020 and signed on their behalf by:



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 2019, which are set out on pages 7 to 14.

**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.

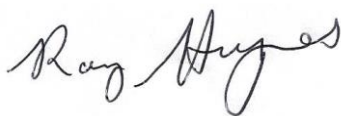
**Independent examiner's statement**

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

28<sup>th</sup> October 2020



SarcoidosisUK

Statement of Financial Activities for the year ended 31 December 2019

	Notes	General Funds 2019 £	Restricted Funds 2019 £	Total 2019 £	Total 2018 £
<b>Incoming Resources</b>					
<b>Incoming resources from generated funds</b>					
Donations	3	196,922	7,000	203,922	128,962
Charitable activities	4	5,446	-	5,446	1,105
Other	5	265	-	265	121
<b>Total incoming resources</b>		<b>202,633</b>	<b>7,000</b>	<b>209,633</b>	<b>130,188</b>
<b>Resources expended</b>					
<b>Less: Expenditure on</b>					
Fundraising	6	40,598	-	40,598	28,794
Ordinary activities	6	60,153	-	60,153	55,613
Charitable activities	7	68,418	7,000	75,418	77,112
<b>Total expenditure</b>		<b>169,169</b>	<b>7,000</b>	<b>176,169</b>	<b>161,519</b>
<b>Net income /(expenditure)</b>		<b>33,464</b>	<b>-</b>	<b>33,464</b>	<b>(31,331)</b>
<b>Net movement in funds</b>		<b>33,464</b>	<b>-</b>	<b>33,464</b>	<b>(31,331)</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		130,286	-	130,286	161,617
<b>Total funds carried forward</b>		<b>163,750</b>	<b>-</b>	<b>163,750</b>	<b>130,286</b>

SarcoidosisUK

Balance Sheet as at 31 December 2019

	Notes	2019 £	2018 £
Fixed assets			
Office equipment	8	2,726	2,509
		<u>2,726</u>	<u>2,509</u>
Current Assets			
Debtors	9	3,887	1,244
Cash at bank and in hand		158,899	188,582
		<u>162,786</u>	<u>189,826</u>
Creditors: amounts falling due within one year	10	1,762	62,049
		<u>1,762</u>	<u>62,049</u>
Net Current Assets		<u>161,024</u>	<u>127,777</u>
<b>Net Assets</b>		<u><b>163,750</b></u>	<u><b>130,286</b></u>
The funds of the charity:			
<b>Unrestricted funds</b>			
General fund	11	163,750	126,676
Designated fund	11	-	3,610
<b>Total funds</b>		<u><b>163,750</b></u>	<u><b>130,286</b></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 October 2019 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. The funds set aside were largely utilised by the end of 2017. In 2019, the residual balance was transferred back to the general fund.

#### (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:

<b>Direct giving</b>	Cash donations and regular gifts are accounted for as received.
<b>Events</b>	Voluntary income arising from major events is recognised in the period in which the event takes place.
<b>Gift Aid</b>	Gift Aid is included based on amounts recoverable at the accounting date.
<b>Legacies</b>	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 2019.

#### (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 5.

#### (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. Statement of Financial Activities – prior year

	Unrestricted 2018 £	Total 2018 £
<b>Incoming Resources</b>		
<b>Incoming resources from generated funds</b>		
Donations	128,962	128,962
Charitable activities	1,105	1,105
Other	121	121
	<hr/>	<hr/>
<b>Total incoming resources</b>	<b>130,188</b>	<b>130,188</b>
<b>Resources expended</b>		
<b>Less: Expenditure on</b>		
Fundraising	28,794	28,794
Ordinary activities	55,613	55,613
Charitable activities	77,112	77,112
	<hr/>	<hr/>
<b>Total expenditure</b>	<b>161,519</b>	<b>161,519</b>
	<hr/>	<hr/>
<b>Net income /(expenditure)</b>	<b>(31,331)</b>	<b>(31,331)</b>
	<hr/>	<hr/>
<b>Net movement in funds</b>	<b>(31,331)</b>	<b>(31,331)</b>
	<hr/>	<hr/>
Reconciliation of funds		
Total funds brought forward	161,617	161,617
	<hr/>	<hr/>
<b>Total funds carried forward</b>	<b>130,286</b>	<b>130,286</b>
	<hr/>	<hr/>

3. Donations

	2019 Unrestricted £	2019 Total £	2018 Total £
Corporate	1,161	1,161	521
In memoriam	14,664	14,664	20,148
Just Giving	48,972	48,972	51,298
Facebook	28,087	28,087	9,106
Grants (Nurse Helpline – Restricted)	-	7,000	-
Legacies	27,000	27,000	-
Virgin Money	4,565	4,565	469
Subscriptions	567	567	349
Individuals	71,906	71,906	47,071
	<u>196,922</u>	<u>203,922</u>	<u>128,962</u>

4. Charitable activities

	2019 Total £	2018 Total £
Merchandise sales	5,446	1,105
	<u>5,446</u>	<u>1,105</u>

5. Other income

	2019 Total £	2018 Total £
Interest on cash deposits	265	121
	<u>265</u>	<u>121</u>

6. Resources Expended – Raising funds

	2019 Fundraising	2019 Ordinary Activities	2019 Total £	2018 Total £
Advertising	95	-	95	156
Accountancy	-	1,440	1,440	480
Bank charges	-	194	194	138
Business rates	-	221	221	-
Conferences	-	834	834	1,072
DBS Checks	-	311	311	-
Depreciation	-	764	764	627
Employer's NI	1,233	1,700	2,933	2,288
Employer's Pension costs	577	765	1,342	670
Facebook	1,653	-	1,653	1,162
Fundraising	5,286	-	5,286	2,537
Insurance	-	1,561	1,561	1,469
Just Giving	615	-	615	655
Legal & professional fees	-	-	-	440
Meetings	-	493	493	894
Membership fees	-	176	176	-
Merchandise expenses	2,876	-	2,876	315
Office rental	-	10,972	10,972	10,800
Computer and IT expenditure	-	2,698	2,698	2,714
Postage	-	1,415	1,415	2,072
Printing	-	152	152	-
Office expenses	-	1,433	1,433	1,721
Recruitment	-	363	363	-
Staff costs	26,854	30,896	57,750	49,583
Stationery	-	282	282	1,209
Subsistence	-	602	602	33
Sundry	-	1,179	1,179	1,251
Surveys	-	-	-	50
Telephone	-	385	385	75
Training	-	695	695	466
Travel expenses	-	622	622	569
Website maintenance	1,409	-	1,409	961
	<b>40,598</b>	<b>60,153</b>	<b>100,751</b>	<b>84,407</b>

7. Resources Expended – Charitable activities

	2019 Unrestricted £	2019 Restricted £	2019 Total £	2018 Total £
Sponsorship	-		-	1,828
Research funded	59,847		59,847	60,194
Educational material	428		428	1,401
Patient days	277		277	-
Nurse helpline	2,004	7,000	9,004	7,282
Support groups	5,862		5,862	6,407
	<b>68,418</b>	<b>7,000</b>	<b>75,418</b>	<b>77,112</b>

8. Fixed assets

	Total £
Cost at 1 January 2019	3,733
Additions in year	981
Disposals in year	-
Cost at 31 December 2019	<b>4,714</b>
Depreciation at 1 January 2019	1,224
Charge in year	764
Disposals in year	-
Depreciation at 31 December 2019	<b>1,988</b>
Net book value at 1 January 2019	<b>2,509</b>
Net book value at 31 December 2019	<b>2,726</b>

9. Debtors

	2019 Total £	2018 Total £
Other debtors	3,887	1,244
	<b>3,887</b>	<b>1,244</b>

10. Creditors falling due within one year

	2019 Total £	2018 Total £
Trustees expenses outstanding	-	80
Accruals	1,440	-
Hull York Medical School	-	59,992
PAYE & NI	-	1,174
Other creditors	322	803
	<u>1,762</u>	<u>62,049</u>

11. Summary of fund movements

	Fund balances brought forward £	Income £	Expenditure £	Transfers £	Fund balances carried forward £
General fund	126,676	202,633	(169,169)	3,610	163,750
Designated fund	3,610		-	(3,610)	-
Restricted funds		7,000	(7,000)	-	-
<b>Total funds</b>	<u>130,286</u>	<u>209,633</u>	<u>(176,169)</u>	<u>-</u>	<u>163,750</u>

12. 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 £154 for the year to 31 December 2019