



Shwachman Diamond Syndrome UK

Annual report for the period 1 November 2020 to 31 October 2021

ABOUT SHWACHMAN DIAMOND SYNDROME

Our mission is to support UK patients and families affected by SDS.

Shwachman Diamond Syndrome (SDS) is a rare genetic disorder that causes problems with the skeleton, digestion, and with the blood / immune system. Research studies have estimated that it occurs in between 1 in 75,000 and 1 in 350,000 births. Patients with SDS can have problems growing, with the absorption of food, will have an impaired immune system from time to time and may have more frequent infections and fevers. In a minority of cases, patients may go on to develop blood cancers such as myelodysplastic syndrome and leukaemia.

THE CHARITY

Shwachman Diamond Syndrome UK is a charity that was formed as a Charitable Incorporated Organisation on 5 November 2015 with registered number 1164269. The Charity has been formed to support patients and families in the UK affected by SDS by:

- promoting access to health and educational services for affected patients throughout the UK,
- supporting research into the pathophysiology of SDS and its current and potential treatment,
- and providing educational resources and activities about SDS for the benefit of families, professionals and the public.

REVIEW OF THE PERIOD

During the period the charity was focused on developing its activities and continuing to gather funds for future distribution. The following individuals served as Trustees during the period:

- Julia Hawkins,
- Kim Wright (retired 30 September 2021),
- Heather Couch,
- Kapil Gotecha,
- Andrew Olding.

FUND RAISING

The Charity raised £28,969 in donations from a variety of individual and corporate sources. The financial year spanned the period impacted by the COVID-19 pandemic which reduced the ability of the Charity and Fundraisers to organise events in support of the Charity. The Trustees would like to thank everyone who has donated and who have held fund-raising events to support Shwachman Diamond Syndrome UK this year.

EXPENDITURE AND COMMITMENTS

The Charity's expenditure in the year constituted funds raised specifically for projects that support the Charity's focus on developing a roadmap that sets out a path to finding a cure for Shwachman Diamond Syndrome.

The Charity has continued to support the work of the Adult clinic in Cambridge. In addition, the Charity retains its commitment to the University of Cambridge to fund a SDS registry hosted by the UK Biobank in Cambridge. This will support Professor Warren's current projects and lay the foundation for future research into SDS by established research teams. The financial commitment is over five years, and is now fully funded.

The Trustees have set aside a small reserve for the limited ongoing costs of the Charity and has committed to support the International Shwachman Diamond Congress which, following its postponement, is now intended to be hosted in Cambridge in 2023.

OUR PLANS FOR 2022

The Trustees will continue to prioritise the following activities:

- Support of the UK patient registry,
- Formation and commissioning of a UK Adult patient clinic,
- Continuing to host family days when pandemic conditions allow,
- Supporting the International Shwachman Diamond Congress in Cambridge, and
- Raising funds to support the work of the charity.

The trustees remain committed to advancing the cause of SDS in the UK and are open to suggestions from the family and patient community on areas that would help the Charity achieve its objective of assisting those who are impacted by this disorder.

Board of Trustees

16 August 2022



CHARITY COMMISSION
FOR ENGLAND AND WALES

Shwachman Diamond Syndrome UK	1164269
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CC16a

Receipts and payments accounts

For the period from	01-Nov-20	To	31-Oct-21
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations	15,829	13,140	-	28,969	10,645
Interest on cash balances	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	15,829	13,140	-	28,969	10,645
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	15,829	13,140	-	28,969	10,645
A3 Payments					
Scientific conferences and research	-	-	-	-	-
Payments to support fund raising activities	-	-	-	-	355
Travel expenses	-	-	-	-	-
Family day, Website and public engagement	-	-	-	-	-
Support of patient clinics	-	-	-	-	300
Legal fees	-	-	-	-	1,410
Literature review	-	2,500	-	2,500	-
Cure roadmap	4,451	8,449	-	12,901	-
	-	-	-	-	-
Sub total	4,451	10,949	-	15,401	2,065
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	4,451	10,949	-	15,401	1,703
Net of receipts/(payments)	11,378	2,190	-	13,568	21,667
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	31,509	8,851	-	40,361	10,114
Cash funds this year end	42,887	11,042	-	53,929	40,361

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Cash at bank	42,887	11,042	-
		-	-	-
		-	-	-
	Total cash funds	42,887	11,042	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities		Fund to which liability relates	Amount due (optional)	When due (optional)
	University of Cambridge	Restricted	29,969	
	Other	Restricted	2,500	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Andrew Olding	16 August 2022	



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity name
Shwachman Diamond UK

On accounts for the year
ended

31 October 2021

Charity no
(if any)

1164269

Set out on pages

1-2

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31 / 10 / 2021**.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination (other than that disclosed below *) which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

* Please delete the words in the brackets if they do not apply.

Signed:

Date: 30/08/2022

Name:

Michael Legge

Relevant professional
qualification(s) or body
(if any):

Diploma in Corporate Governance, Corporate Governance Institute

Address:	Greenleigh Farm
	Chew Magna
	Bristol, BS40 8QR

Section B**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.



CHARITY COMMISSION
FOR ENGLAND AND WALES

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		-	-	-
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			-	-
			-	-
			-	-
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B4 Assets retained for the charity's own use		Fund to which asset belongs	Cost (optional)	Current value (optional)
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			-	-
			-	-
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			-	-
			-	-
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			Andrew Olding	16 August 2022