



Shwachman Diamond Syndrome UK

Annual report for the period 1 November 2022 to 31 October 2023

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,
- Heather Couch,
- Kapil Gotecha,
- Andrew Olding.

FUND RAISING

The Charity raised £61,691 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 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.

In 2023, we made payments to support the International Scientific Congress held in Cambridge, to support fund raising activities and to bring the SDS community together for a family day.

The Trustees have set aside a small reserve for the limited ongoing costs of the Charity.

OUR PLANS FOR 2024

The Trustees will continue to prioritise the following activities:

- Support of the UK patient registry and furthering the Charity's research objectives,
- Formation and commissioning of a UK Adult patient clinic,
- Continuing to host family days when pandemic conditions allow,
- Hosting family days,
- Developing the Charity's fund raising capacity.

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

23 August 2024



CHARITY COMMISSION
FOR ENGLAND AND WALES

Shwachman Diamond Syndrome UK	1164269
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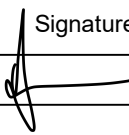
Receipts and payments accounts

For the period from	01-Nov-22	To	31-Oct-23
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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	60,678	1,013	-	61,691	7,294
Interest on cash balances	-	-	-	-	-
Prof Warren fundraising	-	-	-	-	1,000
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	60,678	1,013	-	61,691	8,294
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	60,678	1,013	-	61,691	8,294
A3 Payments					
Scientific conferences and research	5,180	1,024	-	6,204	-
Payments to support fund raising activities	2,175	-	-	2,175	-
Travel expenses	162	-	-	162	-
Family day, Website and public engagement	1,498	-	-	1,498	-
Support of patient clinics	150	-	-	150	-
Marketing materials	803	-	-	803	-
Other expense	40	772	-	812	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	10,008	1,796	-	11,804	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	10,008	1,796	-	11,804	-
Net of receipts/(payments)	50,670	- 782	-	49,887	8,294
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	50,157	12,066	-	62,223	53,929
Cash funds this year end	100,827	11,283	-	112,110	62,223

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	100,827	11,283	-
		-	-	-
		-	-	-
	Total cash funds	100,827	11,283	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
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	2,750	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Andrew Olding	23 Aug 24	



Section A

Independent Examiner's Report

Report to the trustees

Shwachman Diamond Syndrome UK

On accounts for the year
ended

31 October 2023

Charity no
(if any)

1164269

Set out on pages

(remember to include the page numbers of additional sheets)

Responsibilities and
basis of report

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/10/2023**.

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 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.

Signed:

Date: 23/08/2024

Name:

Rosalind Scrope

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

Address:

The Flat Aydon Hose, Corbridge, Northumberland NE45 5PL