



Shwachman Diamond Syndrome UK

Annual report for the period 1 November 2023 to 31 October 2024

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 £54,714 in donations from a variety of individual and corporate sources. Many of the wider SDS communities have held and participated in fund raising activities and continue to enable the

Charity to continue its work. 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

In 2024, we made a substantial payment to support SDS Research led by Professor Warren in Cambridge and further payments to support fund raising activities and to bring the SDS community together for a family day.

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

OUR PLANS FOR 2025

The Trustees will continue to prioritise the following activities:

- Support of the UK patient registry and furthering the Charity's research objectives,
- Supporting families including hosting days for families to come together and share their experiences.

Board of Trustees

27 August 2025



CHARITY COMMISSION
FOR ENGLAND AND WALES

Shwachman Diamond Syndrome UK

1164269

Receipts and payments accounts

CC16a

For the period
from

01-Nov-23

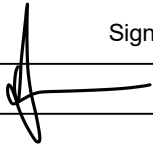
To

31-Oct-24

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	54,714	-	-	54,714	61,691
Interest on cash balances	46	-	-	46	-
Prof Warren fundraising	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	54,760	-	-	54,760	61,691
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	54,760	-	-	54,760	61,691
A3 Payments					
Scientific conferences and research	54,777	5,223	-	60,000	6,204
Payments to support fund raising activities	480	-	-	480	2,175
Travel expenses	117	-	-	117	162
Family day, Website and public engagement	4,726	-	-	4,726	1,498
Support of patient clinics	-	-	-	-	150
Marketing materials	-	-	-	-	803
Other expense	314	-	-	314	812
	-	-	-	-	-
	-	-	-	-	-
Sub total	60,413	5,223	-	65,637	11,804
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	60,413	5,223	-	65,637	11,804
Net of receipts/(payments)	- 5,653	- 5,223	-	- 10,876	49,887
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	100,827	11,283	-	112,110	62,223
Cash funds this year end	95,174	6,060	-	101,234	112,110

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	45,127	6,060	-
	Short term investments	50,046	-	-
		-	-	-
	Total cash funds	95,174	6,060	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets			Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use			Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities			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	27 August 25	

Independent examiner's report to the trustees of Shwachman Diamond Syndrome UK

I report to the trustees on my examination of the accounts of the Shwachman Diamond Syndrome UK (the Trust) for the year ended 31 October 2024.

Responsibilities and basis of report

As the charity trustees of the Trust 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 giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records.

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:



Name: Rosalind Scrope

Address: The Flat Aydon Hose, Corbridge, Northumberland NE45 5PL

Date: 22 Aug 2025