



Shwachman Diamond Syndrome UK

Annual report for the period 1 November 2021 to 31 October 2022

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 £8,294 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.

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 April 2023.

OUR PLANS FOR 2023

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 and supporting the International Shwachman Diamond Congress in Cambridge, and
- 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

3 January 2023

Receipts and payments accounts


For the period from	01-Nov-21	To	31-Oct-22
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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	7,270	24	-	7,294	28,969
Interest on cash balances	-	-	-	-	-
Prof Warren fundraising	-	1,000	-	1,000	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	7,270	1,024	-	8,294	28,969
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	7,270	1,024	-	8,294	28,969
A3 Payments					
Scientific conferences and research	-	-	-	-	-
Payments to support fund raising activities	-	-	-	-	-
Travel expenses	-	-	-	-	-
Family day, Website and public engagement	-	-	-	-	-
Support of patient clinics	-	-	-	-	-
Legal fees	-	-	-	-	-
Literature review	-	-	-	-	2,500
Cure roadmap	-	-	-	-	12,901
	-	-	-	-	-
Sub total	-	-	-	-	15,401
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	-	-	-	-	-
Net of receipts/(payments)	7,270	1,024	-	8,294	
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	42,887	11,042	-	53,929	
Cash funds this year end	50,157	12,066	-	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	50,157	12,066	-
		-	-	-
		-	-	-
	Total cash funds	50,157	12,066	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
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	2,500	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Andrew Olding	3 Jan 23