



Shwachman Diamond Syndrome UK

Annual report for the period 1 November 2019 to 31 October 2020

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,
- Heather Couch (appointed 21 October 2020),
- Kapil Gotecha,
- Keith Laughton (retired 25 March 2020), and
- Andrew Olding.

FUND RAISING

The Charity raised £10,645 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 has been able to commit 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 whilst some further fund-raising is still required, it will be substantially met by the Charity's existing resources.

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 this year, is now intended to be hosted in Cambridge in 2021.

OUR PLANS FOR 2020

The Trustees will continue to prioritise the activities that were initiated in 2019:

- Support of the UK patient registry,
- Hosting a training day for Junior doctors,
- Formation and commissioning of a UK Adult patient clinic,
- Continuing to host family days,
- 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

5 December 2020



CHARITY COMMISSION
FOR ENGLAND AND WALES

Shwachman Diamond Syndrome UK

1164269

Receipts and payments accounts

CC16a

For the period
from

01-Nov-19

To


31-Oct-20

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	4,864	5,781	-	10,645	23,371
Interest on cash balances	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	4,864	5,781	-	10,645	23,371
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	4,864	5,781	-	10,645	23,371
A3 Payments					
Scientific conferences and research	-	-	-	-	-
Payments to support fund raising activities	355	-	-	355	396
Travel expenses	-	-	-	-	60
Family day, Website and public engagement	-	-	-	-	1,248
Support of patient clinics	300	-	-	300	-
Legal fees	1,410	-	-	1,410	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	2,065	-	-	2,065	1,703
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	2,065	-	-	2,065	1,703
Net of receipts/(payments)	2,799	5,781	-	8,580	21,667
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	28,710	3,071	-	31,781	10,114
Cash funds this year end	31,509	8,851	-	40,361	31,781

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	31,509	8,851	-
		-	-	-
		-	-	-
	Total cash funds	31,509	8,851	-
	(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)
			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Andrew Olding	5 Dec 2020