



# Shwachman Diamond Syndrome UK

Annual report for the period 1 November 2018 to 31 October 2019

## ABOUT SHWACHMAN DIAMOND SYNDROME

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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, and will have a reduced 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

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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

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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:

- Nicola Hollands (retired 31 March 2019),
- Julia Hawkins,
- Kim Wright,
- Kapil Gotecha (appointed 21 October 2019),
- Keith Laughton, and
- Andrew Olding.

## **FUND RAISING**

The Charity raised £19,963 in donations from a variety of individual and corporate sources. The Trustees would like to thank Georgina Surguy, Daniel Taylor, Theresa Jurdic, Gideon Glass, and Selina Anslow and many others who have held fund-raising events to support Shwachman Diamond Syndrome UK this year.

## **EXPENDITURE AND COMMITMENTS**

The Charity has finished the year with more funds than it began with. During the year, it has created a website, and hosted a family day, which was well attended by both families and clinicians. The Trustees have set aside a small reserve and committed the existing funds to supporting the creation of a UK patient tissue and clinical registry and to support the International Shwachman Diamond Congress to be hosted in Cambridge in 2020.

The Trustees have worked with Prof. Warren and the Addenbrookes Hospital in Cambridge to encourage the formation of a multi-disciplinary adult patient clinic. An application to commission this clinic as a National Centre, if successful, will place this clinic on a sound financial footing and enable it to receive referrals from patients across the county.

## **OUR PLANS FOR 2020**

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

- Creation of a 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

11 January 2020



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Shwachman Diamond Syndrome UK

1164269

## Receipts and payments accounts

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For the period  
from

01-Nov-18

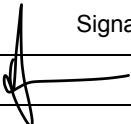
To

31-Oct-19

### Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
<b>A1 Receipts</b>					
Donations	19,963	3,408	-	23,371	3,353
Interest on cash balances	-	-	-	-	4
Bank compensation receipt	-	-	-	-	17
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>19,963</b>	<b>3,408</b>	<b>-</b>	<b>23,371</b>	<b>3,375</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>19,963</b>	<b>3,408</b>	<b>-</b>	<b>23,371</b>	<b>3,375</b>
<b>A3 Payments</b>					
Payments to support scientific conferences and research	-	-	-	-	3,638
Payments to support fund raising activities	59	337	-	396	-
Travel expenses	60	-	-	60	-
Family day, Website and public engagement	1,248	-	-	1,248	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>1,366</b>	<b>337</b>	<b>-</b>	<b>1,703</b>	<b>3,638</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>1,366</b>	<b>337</b>	<b>-</b>	<b>1,703</b>	<b>3,638</b>
<b>Net of receipts/(payments)</b>	<b>18,597</b>	<b>3,071</b>	<b>-</b>	<b>21,667</b>	<b>- 263</b>
<b>A5 Transfers between funds</b>	-	-	-	-	-
<b>A6 Cash funds last year end</b>	<b>10,114</b>	<b>-</b>	<b>-</b>	<b>10,114</b>	<b>10,376</b>
<b>Cash funds this year end</b>	<b>28,710</b>	<b>3,071</b>	<b>-</b>	<b>31,781</b>	<b>10,114</b>

## 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 £
<b>B1 Cash funds</b>	Cash at bank	28,710	3,071	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>28,710</b>	<b>3,071</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>				
<b>B4 Assets retained for the charity's own use</b>				
<b>B5 Liabilities</b>				
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Andrew Olding	11 Jan 2020	