

PUBLIC DISCLOSURE COPY

Form **990**

Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

- ▶ Do not enter Social Security numbers on this form as it may be made public.
- ▶ Information about Form 990 and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2019

Open to Public Inspection

A For the **2019** calendar year, or tax year beginning , **2019**, and ending , **20**

B Check if applicable: <input checked="" type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization KOOLEN-DE VRIES SYNDROME FOUNDATION			D Employer identification number 46-3208388
	Doing Business As			E Telephone number (833) 731-5387
	Number and street (or P.O. box if mail is not delivered to street address)		Room/suite	
	609A PINER ROAD		319	
City or town, state or province, country, and ZIP or foreign postal code WILMINGTON, NC 28409				G Gross receipts \$ 213,930.
F Name and address of principal officer: STEVEN A. SPEIRS 609A PINER ROAD, SUITE 319, WILMINGTON, NC 28409				H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions)
I Tax-exempt status:	<input checked="" type="checkbox"/> 501(c)(3)	<input type="checkbox"/> 501(c) () ◀ (insert no.)	<input type="checkbox"/> 4947(a)(1) or	<input type="checkbox"/> 527
J Website: ▶ KDVSFOUNDATION.ORG				H(c) Group exemption number ▶
K Form of organization:	<input checked="" type="checkbox"/> Corporation	<input type="checkbox"/> Trust	<input type="checkbox"/> Association	<input type="checkbox"/> Other ▶
			L Year of formation: 2013	M State of legal domicile: MO

Part I Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: THE MISSION OF THE KDVS FOUNDATION IS TO EDUCATE, INCREASE AWARENESS, AND PROMOTE RESEARCH FOR THE SUPPORT AND ENRICHMENT OF INDIVIDUALS LIVING WITH KDVS AND THEIR FAMILIES.		
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3 Number of voting members of the governing body (Part VI, line 1a)	3	8.
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	8.
	5 Total number of individuals employed in calendar year 2019 (Part V, line 2a)	5	0.
	6 Total number of volunteers (estimate if necessary)	6	8.
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
b Net unrelated business taxable income from Form 990-T, line 34	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9 Program service revenue (Part VIII, line 2g)	93,914.	198,616.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	9,118.	15,304.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	5.	10.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	103,037.	213,930.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	43,000.	77,000.
	14 Benefits paid to or for members (Part IX, column (A), line 4)	0.	0.
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	0.	0.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	0.	0.
	b Total fundraising expenses (Part IX, column (D), line 25) ▶ 2,059.		
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	20,874.	84,746.
	18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	63,874.	161,746.
19 Revenue less expenses. Subtract line 18 from line 12	39,163.	52,184.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year	End of Year
	21 Total liabilities (Part X, line 26)	104,053.	156,237.
	22 Net assets or fund balances. Subtract line 21 from line 20.	0.	0.
		104,053.	156,237.

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here	▶ Signature of officer	Date			
	▶ Type or print name and title				
Paid Preparer Use Only	Print/Type preparer's name ADAM R SMITH , CPA	Preparer's signature	Date	Check <input type="checkbox"/> if self-employed	PTIN P00958966
	Firm's name ▶ BKD, LLP	Firm's EIN ▶ 44-0160260		Phone no. 719-471-4290	
	Firm's address ▶ 111 SOUTH TEJON ST, SUITE 800 COLORADO SPRINGS, CO 80903-9848				

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

For Paperwork Reduction Act Notice, see the separate instructions. Form **990** (2019)

Cumulative e-File History 2019

FED

Tax Return
6923PB

Return Type
990

Taxpayer
Koolen-de Vries Syndrome Foundation

Submitted Date 2020-06-15 14:51:05

Acknowledgement Date 2020-06-15 15:26:29

Status Accepted

Submission ID 87264120201675000024

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III [X]

1 Briefly describe the organization's mission:

ATTACHMENT 1

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [] Yes [X] No

[] Yes [X] No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [] Yes [X] No

[] Yes [X] No

If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 85,730. including grants of \$ 77,000.) (Revenue \$)

PROMOTING RESEARCH OF KDVS IN FIELDS INCLUDING CLINICAL, DRUG THERAPY, SPEECH THERAPY, AND EPILEPSY.

4b (Code:) (Expenses \$ 48,828. including grants of \$) (Revenue \$ 15,000.)

PROVIDING PATIENT ADVOCACY SUMMITS AND SOCIAL GATHERING EVENTS FOR THE KDVS COMMUNITY AND INTERESTED MEDICAL PROFESSIONALS.

4c (Code:) (Expenses \$ 16,958. including grants of \$) (Revenue \$ 304.)

INCREASING AWARENESS OF KDVS IN BOTH THE GENERAL POPULATION AND MEDICAL PROFESSION.

4d Other program services (Describe on Schedule O.)

(Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 151,516.

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A.</i>	X	
2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> (see instructions)?	X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I.</i>		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II.</i>		X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III</i>		
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I.</i>		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II.</i>		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III.</i>		X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV.</i>		X
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? <i>If "Yes," complete Schedule D, Part V.</i>		X
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI.</i>		X
b Did the organization report an amount for investments-other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII.</i>		X
c Did the organization report an amount for investments-program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII.</i>		X
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX.</i>		X
e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X.</i>		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X.</i>		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII.</i>		X
b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional.</i>		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E.</i>		X
14a Did the organization maintain an office, employees, or agents outside of the United States?.		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV.</i>	X	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV.</i>	X	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV.</i>		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i> (see instructions).		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II.</i>		X
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III.</i>		X
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H.</i>		X
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II.</i>		X

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question number, Question text, Yes, No. Rows 22-38 covering various organizational requirements.

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response or note to any line in this Part V []

Table with 3 columns: Question number, Question text, Yes, No. Rows 1a-1c regarding Form 1096 and backup withholding rules.

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

		Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return. 2a 0.		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)	2b	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a	X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a	X
b	If "Yes," enter the name of the foreign country ▶ _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b	X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c	
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?	6a	X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b	
7 Organizations that may receive deductible contributions under section 170(c).			
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	X
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c	X
d	If "Yes," indicate the number of Forms 8282 filed during the year 7d		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e	X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f	X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g	
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h	
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	8	
9 Sponsoring organizations maintaining donor advised funds.			
a	Did the sponsoring organization make any taxable distributions under section 4966?	9a	
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b	
10 Section 501(c)(7) organizations. Enter:			
a	Initiation fees and capital contributions included on Part VIII, line 12	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b	
11 Section 501(c)(12) organizations. Enter:			
a	Gross income from members or shareholders	11a	
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year 12b		
13 Section 501(c)(29) qualified nonprofit health insurance issuers.			
a	Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.	13a	
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans 13b		
c	Enter the amount of reserves on hand 13c		
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a	X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	14b	
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see instructions and file Form 4720, Schedule N.	15	X
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	16	X

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions.

Check if Schedule O contains a response or note to any line in this Part VI [X]

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a (8), 1b (8), 2 (X), 3 (X), 4 (X), 5 (X), 6 (X), 7a (X), 7b (X), 8a (X), 8b (X), 9 (X).

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

Table with 3 columns: Question, Yes, No. Rows include: 10a (X), 10b, 11a (X), 11b, 12a (X), 12b, 12c, 13 (X), 14 (X), 15a, 15b, 16a (X), 16b.

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed
18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (Section 501(c) (3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

Check if Schedule O contains a response or note to any line in this Part VII

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See instructions for the order in which to list the persons above.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) PATTY TIBERG PRESIDENT	4.00 0.	X		X				0.	0.	0.
(2) ANGELA DEJONG BOARD MEMBER	2.00 0.	X						0.	0.	0.
(3) ALAYNA HAYNAM VICE-PRESIDENT	5.00 0.	X		X				0.	0.	0.
(4) STEVEN TIBERG BOARD MEMBER	2.00 0.	X						0.	0.	0.
(5) MANDY BYLUND BOARD MEMBER	5.00 0.	X						0.	0.	0.
(6) NEAL DERMERER BOARD MEMBER	1.00 0.	X						0.	0.	0.
(7) STEVEN A. SPEIRS TREASURER	3.00 0.	X		X				0.	0.	0.
(8) ALICIA HOLCOMBE BOARD MEMBER	2.00 0.	X						0.	0.	0.
(9)										
(10)										
(11)										
(12)										
(13)										
(14)										

Part VIII Statement of Revenue

Check if Schedule O contains a response or note to any line in this Part VIII

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns	1a					
	b	Membership dues	1b					
	c	Fundraising events	1c					
	d	Related organizations	1d					
	e	Government grants (contributions) . .	1e					
	f	All other contributions, gifts, grants, and similar amounts not included above .	1f	198,616.				
	g	Noncash contributions included in lines 1a-1f.	1g	\$				
	h	Total. Add lines 1a-1f ▶		198,616.				
	Program Service Revenue	2a	AWARENESS PRODUCT	Business Code	813212	304.	304.	
b		SUMMIT REGISTRATION FEE	Business Code	813212	15,000.	15,000.		
c								
d								
e								
f		All other program service revenue						
g		Total. Add lines 2a-2f ▶			15,304.			
Other Revenue		3	Investment income (including dividends, interest, and other similar amounts). ▶			10.		10.
	4	Income from investment of tax-exempt bond proceeds . ▶			0.			
	5	Royalties ▶			0.			
	6a	Gross rents	6a	(i) Real	(ii) Personal			
	b	Less: rental expenses	6b					
	c	Rental income or (loss)	6c					
	d	Net rental income or (loss) ▶				0.		
	7a	Gross amount from sales of assets other than inventory	7a	(i) Securities	(ii) Other			
	b	Less: cost or other basis and sales expenses . .	7b					
	c	Gain or (loss)	7c					
	d	Net gain or (loss) ▶				0.		
8a	Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18	8a		0.				
			8b	0.				
			c	Net income or (loss) from fundraising events. ▶		0.		
9a	Gross income from gaming activities. See Part IV, line 19	9a		0.				
			9b	0.				
			c	Net income or (loss) from gaming activities. ▶		0.		
10a	Gross sales of inventory, less returns and allowances	10a		0.				
			10b	0.				
			c	Net income or (loss) from sales of inventory. ▶		0.		
Miscellaneous Revenue	11a		Business Code					
	b							
	c							
	d	All other revenue						
	e	Total. Add lines 11a-11d ▶				0.		
12	Total revenue. See instructions ▶			213,930.	15,304.		10.	

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	0.			
2 Grants and other assistance to domestic individuals. See Part IV, line 22	0.			
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	77,000.	77,000.		
4 Benefits paid to or for members	0.			
5 Compensation of current officers, directors, trustees, and key employees	0.			
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0.			
7 Other salaries and wages	0.			
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	0.			
9 Other employee benefits	0.			
10 Payroll taxes	0.			
11 Fees for services (nonemployees):				
a Management	0.			
b Legal	9,587.	7,184.	2,403.	
c Accounting	0.			
d Lobbying	0.			
e Professional fundraising services. See Part IV, line 17.	0.			
f Investment management fees	0.			
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.)	0.			
12 Advertising and promotion	7,415.	7,415.		
13 Office expenses	15,038.	10,264.	2,715.	2,059.
14 Information technology	3,348.	1,881.	1,467.	
15 Royalties	0.			
16 Occupancy	0.			
17 Travel	13,108.	13,108.		
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0.			
19 Conferences, conventions, and meetings	36,250.	34,664.	1,586.	
20 Interest	0.			
21 Payments to affiliates	0.			
22 Depreciation, depletion, and amortization	0.			
23 Insurance	0.			
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a _____				
b _____				
c _____				
d _____				
e All other expenses _____				
25 Total functional expenses. Add lines 1 through 24e	161,746.	151,516.	8,171.	2,059.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)	0.			

Part X Balance Sheet

Check if Schedule O contains a response or note to any line in this Part X

		(A) Beginning of year		(B) End of year	
Assets	1 Cash - non-interest-bearing	104,053.	1	106,842.	
	2 Savings and temporary cash investments	0.	2	49,395.	
	3 Pledges and grants receivable, net	0.	3	0.	
	4 Accounts receivable, net.	0.	4	0.	
	5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons	0.	5	0.	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)	0.	6	0.	
	7 Notes and loans receivable, net	0.	7	0.	
	8 Inventories for sale or use	0.	8	0.	
	9 Prepaid expenses and deferred charges	0.	9	0.	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a			
	b Less: accumulated depreciation	10b	0.	10c	0.
	11 Investments - publicly traded securities	0.	11	0.	
	12 Investments - other securities. See Part IV, line 11	0.	12	0.	
	13 Investments - program-related. See Part IV, line 11	0.	13	0.	
	14 Intangible assets	0.	14	0.	
	15 Other assets. See Part IV, line 11	0.	15	0.	
16 Total assets. Add lines 1 through 15 (must equal line 33)	104,053.	16	156,237.		
Liabilities	17 Accounts payable and accrued expenses	0.	17	0.	
	18 Grants payable	0.	18	0.	
	19 Deferred revenue	0.	19	0.	
	20 Tax-exempt bond liabilities	0.	20	0.	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D	0.	21	0.	
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons	0.	22	0.	
	23 Secured mortgages and notes payable to unrelated third parties	0.	23	0.	
	24 Unsecured notes and loans payable to unrelated third parties	0.	24	0.	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D	0.	25	0.	
	26 Total liabilities. Add lines 17 through 25	0.	26	0.	
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.				
	27 Net assets without donor restrictions	104,053.	27	138,284.	
	28 Net assets with donor restrictions	0.	28	17,953.	
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.				
	29 Capital stock or trust principal, or current funds		29		
	30 Paid-in or capital surplus, or land, building, or equipment fund		30		
	31 Retained earnings, endowment, accumulated income, or other funds		31		
	32 Total net assets or fund balances	104,053.	32	156,237.	
33 Total liabilities and net assets/fund balances	104,053.	33	156,237.		

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response or note to any line in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1	213,930.
2	Total expenses (must equal Part IX, column (A), line 25)	2	161,746.
3	Revenue less expenses. Subtract line 2 from line 1	3	52,184.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	104,053.
5	Net unrealized gains (losses) on investments	5	0.
6	Donated services and use of facilities	6	0.
7	Investment expenses	7	0.
8	Prior period adjustments	8	0.
9	Other changes in net assets or fund balances (explain on Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	156,237.

Part XII Financial Statements and Reporting

Check if Schedule O contains a response or note to any line in this Part XII.

- 1** Accounting method used to prepare the Form 990: Cash Accrual Other _____
If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.
- 2a** Were the organization's financial statements compiled or reviewed by an independent accountant?
If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:
 Separate basis Consolidated basis Both consolidated and separate basis
- b** Were the organization's financial statements audited by an independent accountant?
If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:
 Separate basis Consolidated basis Both consolidated and separate basis
- c** If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?
If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.
- 3a** As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?
- b** If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits

	Yes	No
2a		X
2b		X
2c		
3a		X
3b		

SCHEDULE A
(Form 990 or 990-EZ)

Public Charity Status and Public Support

OMB No. 1545-0047

2019

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

▶ Attach to Form 990 or Form 990-EZ.

▶ Go to www.irs.gov/Form990 for instructions and the latest information.

Name of the organization KOOLEN-DE VRIES SYNDROME FOUNDATION	Employer identification number 46-3208388
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Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1 A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2 A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990 or 990-EZ).)
- 3 A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4 A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: _____
- 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6 A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7 An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8 A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9 An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: _____
- 10 An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**.
Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
 - a **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
 - b **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
 - c **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
 - d **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
 - e Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
 - f Enter the number of supported organizations
 - g Provide the following information about the supported organization(s).

	(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
				Yes	No		
(A)							
(B)							
(C)							
(D)							
(E)							
Total							

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule A (Form 990 or 990-EZ) 2019

JSA
9E1210 1.000

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
 (Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	1,000.	10,000.	25,067.	93,914.	198,616.	328,597.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0.
3 The value of services or facilities furnished by a governmental unit to the organization without charge						0.
4 Total. Add lines 1 through 3.	1,000.	10,000.	25,067.	93,914.	198,616.	328,597.
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f).						48,423.
6 Public support. Subtract line 5 from line 4						280,174.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
7 Amounts from line 4.	1,000.	10,000.	25,067.	93,914.	198,616.	328,597.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources				5.	10.	15.
9 Net income from unrelated business activities, whether or not the business is regularly carried on						0.
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						0.
11 Total support. Add lines 7 through 10						328,612.
12 Gross receipts from related activities, etc. (see instructions)					12	29,991.
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f)).	14	85.26%
15 Public support percentage from 2018 Schedule A, Part II, line 14	15	87.48%
16a 33 1/3% support test - 2019. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here . The organization qualifies as a publicly supported organization.		<input checked="" type="checkbox"/>
b 33 1/3% support test - 2018. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here . The organization qualifies as a publicly supported organization		<input type="checkbox"/>
17a 10%-facts-and-circumstances test - 2019. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here . Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization.		<input type="checkbox"/>
b 10%-facts-and-circumstances test - 2018. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here . Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization		<input type="checkbox"/>
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions		<input type="checkbox"/>

Part III Support Schedule for Organizations Described in Section 509(a)(2)
 (Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II.
 If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5.						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b.						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
9 Amounts from line 6.						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**

Section C. Computation of Public Support Percentage

15 Public support percentage for 2019 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2018 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2019 (line 10c, column (f), divided by line 13, column (f)),	17	%
18 Investment income percentage from 2018 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2019. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization .

b 33 1/3% support tests - 2018. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

Part IV Supporting Organizations

(Complete only if you checked a box in line 12 on Part I. If you checked 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

	Yes	No
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>		
b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>		
c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i>		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i>		
b Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>		
c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>		
10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

Part IV Supporting Organizations (continued)

	Yes	No
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?	11 a	
b A family member of a person described in (a) above?	11 b	
c A 35% controlled entity of a person described in (a) or (b) above? <i>If "Yes" to a, b, or c, provide detail in Part VI.</i>	11 c	

Section B. Type I Supporting Organizations

	Yes	No
1 Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>	1	
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.</i>	2	

Section C. Type II Supporting Organizations

	Yes	No
1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>	1	

Section D. All Type III Supporting Organizations

	Yes	No
1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?	1	
2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>	2	
3 By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>	3	

Section E. Type III Functionally Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).			
a <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.			
b <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.			
c <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).			
2 Activities Test. Answer (a) and (b) below.		Yes	No
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>	2a		
b Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>	2b		
3 Parent of Supported Organizations. Answer (a) and (b) below.			
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>	3a		
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>	3b		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

1 Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI). **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1 Net short-term capital gain	1		
2 Recoveries of prior-year distributions	2		
3 Other gross income (see instructions)	3		
4 Add lines 1 through 3.	4		
5 Depreciation and depletion	5		
6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6		
7 Other expenses (see instructions)	7		
8 Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)	8		

Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):			
a Average monthly value of securities	1a		
b Average monthly cash balances	1b		
c Fair market value of other non-exempt-use assets	1c		
d Total (add lines 1a, 1b, and 1c)	1d		
e Discount claimed for blockage or other factors (explain in detail in Part VI):			
2 Acquisition indebtedness applicable to non-exempt-use assets	2		
3 Subtract line 2 from line 1d.	3		
4 Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions).	4		
5 Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6 Multiply line 5 by .035.	6		
7 Recoveries of prior-year distributions	7		
8 Minimum Asset Amount (add line 7 to line 6)	8		

Section C - Distributable Amount			Current Year
1 Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2 Enter 85% of line 1.	2		
3 Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4 Enter greater of line 2 or line 3.	4		
5 Income tax imposed in prior year	5		
6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6		

7 Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D - Distributions	Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI). See instructions.	
7 Total annual distributions. Add lines 1 through 6.	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	
9 Distributable amount for 2019 from Section C, line 6	
10 Line 8 amount divided by line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2019	(iii) Distributable Amount for 2019
1 Distributable amount for 2019 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2019 (reasonable cause required - explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2019			
a From 2014			
b From 2015			
c From 2016			
d From 2017			
e From 2018			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2019 distributable amount			
i Carryover from 2014 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4 Distributions for 2019 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2019 distributable amount			
c Remainder. Subtract lines 4a and 4b from 4.			
5 Remaining underdistributions for years prior to 2019, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.			
6 Remaining underdistributions for 2019. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7 Excess distributions carryover to 2020. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2015			
b Excess from 2016			
c Excess from 2017			
d Excess from 2018			
e Excess from 2019			

Part VI **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

Schedule of Contributors

2019

▶ Attach to Form 990, Form 990-EZ, or Form 990-PF.
 ▶ Go to www.irs.gov/Form990 for the latest information.

Name of the organization KOOLEN-DE VRIES SYNDROME FOUNDATION	Employer identification number 46-3208388
---	--

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

501(c)(3) (enter number) organization

4947(a)(1) nonexempt charitable trust **not** treated as a private foundation

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

4947(a)(1) nonexempt charitable trust treated as a private foundation

501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**.

Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of **(1)** \$5,000; or **(2)** 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I, II, and III.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year ▶ \$ _____

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990, 990-EZ, or 990-PF), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

Name of organization **KOOLEN-DE VRIES SYNDROME FOUNDATION**

Employer identification number
46-3208388

Part I **Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1		\$ 20,140.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2		\$ 25,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3		\$ 12,500.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4		\$ 5,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5		\$ 5,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
6		\$ 6,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization KOOLEN-DE VRIES SYNDROME FOUNDATION

Employer identification number

46-3208388

Part II Noncash Property (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____

Name of organization KOOLEN-DE VRIES SYNDROME FOUNDATION

Employer identification number
46-3208388

Part III Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of *exclusively* religious, charitable, etc., contributions of **\$1,000 or less** for the year. (Enter this information once. See instructions.) ▶ \$ _____
Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
_____	_____ _____	_____ _____	_____ _____

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
_____ _____ _____	_____ _____ _____

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
_____	_____ _____	_____ _____	_____ _____

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
_____ _____ _____	_____ _____ _____

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
_____	_____ _____	_____ _____	_____ _____

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
_____ _____ _____	_____ _____ _____

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
_____	_____ _____	_____ _____	_____ _____

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
_____ _____ _____	_____ _____ _____

**SCHEDULE F
(Form 990)**

Statement of Activities Outside the United States

OMB No. 1545-0047

2019

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

▶ **Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.**
▶ **Attach to Form 990.**
▶ **Go to www.irs.gov/Form990 for instructions and the latest information.**

Name of the organization

KOOLEN-DE VRIES SYNDROME FOUNDATION

Employer identification number

46-3208388

Part I General Information on Activities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

- 1 **For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? **Yes** **No**
- 2 **For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

3 **Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
(1) EUROPE	0.	0.	GRANTMAKING		77,000.
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Subtotal					77,000.
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					77,000.

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule F (Form 990) 2019

Part II **Grants and Other Assistance to Organizations or Entities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)			EUROPE/ICELAND/GREENLAND	DRUG THERAPY RESEARCH	77,000.	WIRE TRANSFE			
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter **1.**

3 Enter total number of other organizations or entities

Part III **Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 16.
Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

Part IV Foreign Forms

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* Yes No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)* Yes No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see Instructions for Form 5471)* Yes No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)* Yes No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* Yes No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990)* Yes No

Part V Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information (see instructions).

FORM 990 SCHEDULE F PART I, LINE 2

INDIVIDUALS OR ORGANIZATIONS REQUESTING FINANCIALS ASSISTANCE FROM THE
FOUNDATION MUST DO THE FOLLOWING BEFORE ASSISTANCE IS GRANTED:

1. SUBMIT A RESEARCH PROJECT PROPOSAL DESCRIBING THE RESEARCH BEING
CONDUCTED, AND THE INTENDED OUTCOMES. AS PART OF THE PROPOSAL, A DETAILED
BUDGET REQUESTING A SPECIFIC AMOUNT AND ITEMIZING THE ANTICIPATED
EXPENSES ARE INCLUDED.
2. THE RESEARCH PROPOSAL IS REVIEWED AND VOTED ON BY THE BOARD OF
DIRECTORS AND MEDICAL ADVISORY BOARD.
3. UPON APPROVAL BY BOTH BOARDS, THE GRANT/ASSISTANCE REQUEST IS GRANTED
OR DENIED.
4. UPON COMPLETION OF THE RESEARCH PROJECT, A REPORT FROM THE RECIPIENT
IS REQUIRED WHICH OUTLINES THE FINDINGS OF THEIR RESEARCH AND THE USE OF
THE FUNDING RECEIVED FROM THE FOUNDATION.

**SCHEDULE O
(Form 990 or 990-EZ)**

Department of the Treasury
Internal Revenue Service

Name of the organization

KOOLEN-DE VRIES SYNDROME FOUNDATION

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2019

**Open to Public
Inspection**

Employer identification number

46-3208388

FORM 990, PART VI, SECTION A, LINE 2

THE FOLLOWING INDIVIDUALS ON THE BOARD OF DIRECTORS HAVE A FAMILIAL
RELATIONSHIP:

PATTY TIBERG AND STEVEN TIBERG ARE RELATED

FORM 990, PART VI, SECTION B, LINE 11B

A COPY OF THE 990 WAS MADE AVAILABLE TO ALL BOARD MEMBERS PRIOR TO BEING
FILED.

FORM 990, PART VI, SECTION B, LINES 15A & 15B

REVIEW OF COMPENSATION:

CURRENTLY, THERE ARE NO OFFICERS OR BOARD MEMBERS WHO ARE COMPENSATED BY
THE FOUNDATION.

FORM 990, PART VI, SECTION C, LINE 19

THE ORGANIZATION'S FINANCIAL STATEMENTS AND OTHER POLICIES ARE MADE
AVAILABLE TO THE PUBLIC UPON REQUEST.

ATTACHMENT 1

FORM 990, PART III, LINE 1 - ORGANIZATION'S MISSION

THE KOOLEN-DE VRIES SYNDROME FOUNDATION IS AN INTERNATIONAL GROUP
THAT SUPPORTS, INFORMS, AND NETWORKS WITH ANYONE AFFECTED BY
KOOLEN-DE VRIES SYNDROME (KDVS) AND WITH ANY INTERESTED
PROFESSIONALS. THE FOUNDATION'S ACTIVITIES INCLUDE SOCIAL
GATHERINGS, PATIENT ADVOCACY SUMMITS, SUPPORTING RESEARCH, AND
PROVIDING INFORMATION REGARDING KDVS TO BOTH THE GENERAL POPULATION

Name of the organization KOOLEN-DE VRIES SYNDROME FOUNDATION	Employer identification number 46-3208388
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ATTACHMENT 1 (CONT'D)

FORM 990, PART III, LINE 1 - ORGANIZATION'S MISSION

AND MEDICAL PROFESSIONALS.