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Form 990

Department of the TreasuryInternal 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.

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

OMB No. 1545-0047

2019

Open to Public Inspection

A For the 2019 calendar year, or tax year beginning 01-01-2019 , and ending 12-31-2019

B Check if applicable:

☒ Address change

☐ Name change

☐ Initial return

☐ Final return/terminated

☐ Amended return

☐ Application pending

C Name of organization

Koolen-de Vries Syndrome Foundation

% ANDY SPEIRS

Doing business as

Number and street (or P.O. box if mail is not delivered to street address)

Room/suite

609A Piner Road Suite 319

City or town, state or province, country, and ZIP or foreign postal code

Wilmington, NC 28409

F Name and address of principal officer:

STEVEN A SPEIRS

609A Piner Road Suite 319

Wilmington, NC 28409

D Employer identification number

46-3208388

E Telephone number

(833) 731-5387

G Gross receipts \$

213,930

H(a) Is this a group return for subordinates?

☐ Yes ☒ No

H(b) Are all subordinates included?

☐ Yes ☐ No

If "No," attach a list. (see instructions)

H(c) Group exemption number ▶

I Tax-exempt status: ☒ 501(c)(3) ☐ 501(c) () ◀ (insert no.) ☐ 4947(a)(1) or ☐ 527

J Website: ▶

kdvsfoundation.org

K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ 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 ☐ 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)

8

4 Number of independent voting members of the governing body (Part VI, line 1b)

8

5 Total number of individuals employed in calendar year 2019 (Part V, line 2a)

0

6 Total number of volunteers (estimate if necessary)

8

7a Total unrelated business revenue from Part VIII, column (C), line 12

0

7b Net unrelated business taxable income from Form 990-T, line 39

Revenue

8 Contributions and grants (Part VIII, line 1h)

93,914

9 Program service revenue (Part VIII, line 2g)

9,118

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)

5

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)

0

12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)

103,037

Expenses

13 Grants and similar amounts paid (Part IX, column (A), lines 1–3)

43,000

14 Benefits paid to or for members (Part IX, column (A), line 4)

0

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)

0

16a Professional fundraising fees (Part IX, column (A), line 11e)

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

18 Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)

63,874

19 Revenue less expenses. Subtract line 18 from line 12

39,163

Net Assets or Fund Balances

20 Total assets (Part X, line 16)

104,053

21 Total liabilities (Part X, line 26)

0

22 Net assets or fund balances. Subtract line 21 from line 20

104,053

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

STEVEN A SPEIRS Treasurer

Type or print name and title

2020-11-03

Date

Paid Preparer Use Only

Print/Type preparer's name

Firm's name ▶ BKD LLP

Firm's address ▶ 111 SOUTH TEJON ST SUITE 800

COLORADO SPRINGS, CO 809039848

Preparer's signature

Firm's EIN ▶

Phone no. (719) 471-4290

Date

Check ☐ if self-employed

PTIN P00958966

May the IRS discuss this return with the preparer shown above? (see instructions)

☒ Yes ☐ No

For Paperwork Reduction Act Notice, see the separate instructions.

Cat. No. 11282Y

Form 990 (2019)

Part III Statement of Program Service AccomplishmentsCheck if Schedule O contains a response or note to any line in this Part III ☒**1** Briefly describe the 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 AND MEDICAL PROFESSIONALS.

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 ☒ 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 ☒ 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 \$)
See Additional Data

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

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

4d Other program services (Describe in 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)? If "Yes," complete Schedule A 	1 Yes	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 	2 Yes	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3	No
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? If "Yes," complete Schedule C, Part II	4	No
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? If "Yes," complete Schedule C, Part III	5	
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? If "Yes," complete Schedule D, Part I	6	No
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7	No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8	No
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? If "Yes," complete Schedule D, Part IV	9	No
10 Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi endowments? If "Yes," complete Schedule D, Part V	10	No
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? If "Yes," complete Schedule D, Part VI.	11a	No
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? If "Yes," complete Schedule D, Part VII	11b	No
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? If "Yes," complete Schedule D, Part VIII	11c	No
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? If "Yes," complete Schedule D, Part IX	11d	No
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	No
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)? If "Yes," complete Schedule D, Part X	11f	No
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	12a	No
b Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b	No
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	No
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	No
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? If "Yes," complete Schedule F, Parts I and IV 	14b Yes	
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? If "Yes," complete Schedule F, Parts II and IV 	15 Yes	
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? If "Yes," complete Schedule F, Parts III and IV 	16	No
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? If "Yes," complete Schedule G, Part I (see instructions)	17	No
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	18	No
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III	19	No
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	
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? If "Yes," complete Schedule I, Parts I and II	21	No

Part IV Checklist of Required Schedules (continued)

		Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22	No
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23	No
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>	24a	No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b	
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c	
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d	
25a	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a	No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b	No
26	Did the organization report any amount on Part X, line 5 or 22 for receivables from or 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? <i>If "Yes," complete Schedule L, Part II</i>	26	No
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27	No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
a	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>	28a	No
b	A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>	28b	No
c	A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>	28c	No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29	No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30	No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31	No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32	No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33	No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>	34	No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a	No
b	If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b	
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36	
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37	No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O.	38	Yes

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	1a	4
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable	1b	0
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	

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

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	No
b If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in 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	No
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	No
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?			5b	No
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	No
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	No
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	No
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	No
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?			7f	No
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	No
b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in 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	No
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	No

Part VI

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

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

Section A. Governing Body and Management

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O.	8	
1b	Enter the number of voting members included in line 1a, above, who are independent	8	
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	2	Yes
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?	3	No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4	No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5	No
6	Did the organization have members or stockholders?	6	No
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?	7a	No
7b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7b	No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a	The governing body?	8a	Yes
b	Each committee with authority to act on behalf of the governing body?	8b	Yes
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O	9	No

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

		Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a	No
10b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	10b	
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a	Yes
11b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.		
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	No
12b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	
12c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	12c	
13	Did the organization have a written whistleblower policy?	13	No
14	Did the organization have a written document retention and destruction policy?	14	No
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
15a	The organization's CEO, Executive Director, or top management official	15a	
15b	Other officers or key employees of the organization	15b	
	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).		
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?	16a	No
16b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?	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 Form 1023 (or 1024-A if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.

☐ Own website ☐ Another's website ☒ Upon request ☐ Other (explain in Schedule O)

19 Describe in 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:
 ANDY SPEIRS 609A PINER ROAD SUITE 319 Wilmington, NC 28409 (801) 643-6004

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 ☐

a 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, or 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.

[illegible]

Part VII

1b Sub-Total			
c Total from continuation sheets to Part VII, Section A			
d Total (add lines 1b and 1c)	0	0	0

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization ► 0

		Yes	No
3	Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>	3	No
4	For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>	4	No
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>	5	No

Section B. Independent Contractors

Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A)	(B)	(C)
Name and business address	Description of services	Compensation

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ▶ 0

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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						Business Code					
	2a AWARENESS PRODUCT					813212	304	304			
	b SUMMIT REGISTRATION FEE					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					
						(i) Real	(ii) Personal				
	6a Gross rents					6a					
	b Less: rental expenses					6b					
	c Rental income or (loss)					6c	0	0			
	d Net rental income or (loss) ▶					0					
						(i) Securities	(ii) Other				
	7a Gross amount from sales of assets other than inventory					7a					
	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				
	b Less: direct expenses					8b	0				
	c Net income or (loss) from fundraising events . . . ▶					0					
	9a Gross income from gaming activities. See Part IV, line 19					9a	0				
	b Less: direct expenses					9b	0				
	c Net income or (loss) from gaming activities . . . ▶					0					
	10a Gross sales of inventory, less returns and allowances . . .					10a	0				
b Less: cost of goods sold . . .					10b	0					
c Net income or (loss) from sales of inventory . . . ▶					0						
Miscellaneous Revenue					Business Code						
11a											
b											
c											
d All other revenue											
e Total. Add lines 11a-11d ▶					0						
12 Total revenue. See instructions ▶					213,930	15,304			10		

Form 990 (2019)

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 (non-employees):				
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			0
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in 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 ☐ if following SOP 98-2 (ASC 958-720).				

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part IX ☐

		(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 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	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 34)	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 ☒ 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 ☐ 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 AssetsCheck 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 33, column (A))	4	104,053
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	156,237

Part XII Financial Statements and ReportingCheck if Schedule O contains a response or note to any line in this Part XII ☐

	Yes	No
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		No
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		No
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 in 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?		No
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 in Schedule O and describe any steps taken to undergo such audits.		

Additional Data

Software ID:

Software Version:

EIN: 46-3208388

Name: Koolen-de Vries Syndrome Foundation

Form 990 (2019)

Form 990, Part III, Line 4a:

Promoting research of KdVS in fields including clinical, drug therapy, speech therapy, and epilepsy.

Form 990, Part III, Line 4b:

Providing patient advocacy summits and social gathering events for the KdVS community and interested medical professionals.

Form 990, Part III, Line 4c:

Increasing awareness of KdVS in both the general population and medical profession.

SCHEDULE A
(Form 990 or 990EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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.

OMB No. 1545-0047

2019

Open to Public Inspection

Name of the organization
Koolen-de Vries Syndrome Foundation

Employer identification number
46-3208388

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 **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		
Total						

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 failed 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 grant.") . . .	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 ▶ ☐						
Section C. Computation of Public Support Percentage						
14 Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f))					14	85.260 %
15 Public support percentage for 2018 Schedule A, Part II, line 14					15	87.480 %
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 ▶ ☒						
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 ▶ ☐						
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 ▶ ☐						
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 ▶ ☐						
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 ▶ ☐						

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	0 %
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 on line 12 of 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>		
1		
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>		
2		
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>		
3a		
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>		
3b		
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>		
3c		
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>		
4a		
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>		
4b		
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>		
4c		
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>		
5a		
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?		
5b		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
5c		
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>		
6		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (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>		
7		
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>		
8		
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>		
9a		
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>		
9b		
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>		
9c		
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 line 10b below.</i>		
10a		
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>		
10b		

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?		
b A family member of a person described in (a) above?		
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>		

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>		
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>		

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>		

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?		
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>		
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>		

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 ☐ The organization satisfied the Activities Test. Complete line 2 below.		
b ☐ The organization is the parent of each of its supported organizations. Complete line 3 below.		
c ☐ 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.		
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>		
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>		
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>		
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>		

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):	1	
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. If the amount is greater than zero, explain in Part VI. See instructions.			
6 Remaining underdistributions for 2019. Subtract lines 3h and 4b from line 1. If the amount is 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.			

Additional Data

Software ID:
Software Version:
EIN: 46-3208388
Name: Koolen-de Vries Syndrome Foundation

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).

Facts And Circumstances Test

SCHEDULE F (Form 990)	Statement of Activities Outside the United States ▶ Complete if the organization answered "Yes" to 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.	OMB No. 1545-0047
		2019 Open to Public Inspection

Name of the organization Koolen-de Vries Syndrome Foundation	Employer identification number 46-3208388
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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 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
Europe (Including Iceland and Greenland)			Grantmaking		77,000
3a Sub-total					77,000
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					77,000

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)
			Europe (Including Iceland and Greenland)	Doctors David Koolen, Bert de Vries, and Nael Kasri are leading a research team that studies Koolen-de Vries Syndrome. In July of 2019, the foundation transferred \$77,000 to help fund their research projects. Their current research involves comparing the activity of KdVS neurons and controls. The research is laying important ground work to understand the biological mechanisms underpinning KdVS. Having identified the differences in gene expression in KdVS neurons, their next step is identifying FDA approved substances that help mitigate the negative effects of KdVS in the brain.	77,000	Wire Transfe			

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.
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Part III can be duplicated if additional space is needed.

[illegible]

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.

990 Schedule F, Supplemental Information

Return Reference	Explanation
Form 990 Schedule F Part I, Line 2	Individuals or organizations requesting financial 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.

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

OMB No. 1545-0047

2019

Open to Public Inspection

Employer identification number

46-3208388

990 Schedule O, Supplemental Information

Return Reference	Explanation
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

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Section B, Line 11b	A copy of the 990 was made available to all board members prior to being filed.

990 Schedule O, Supplemental Information

Return Reference	Explanation
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.

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Section C, Line 19	The organization's financial statements and other policies are made available to the public upon request.