

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.

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
CORNELIA DE LANGE SYNDROME FOUNDATION

Doing business as

Number and street (or P.O. box if mail is not delivered to street address) Room/suite
30 Tower Lane

City or town, state or province, country, and ZIP or foreign postal code
AVON, CT 06001

D Employer identification number
06-1057497

E Telephone number
(860) 676-8166

G Gross receipts \$ 2,329,442

F Name and address of principal officer:
Bonnie Royster

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: ▶ WWW.CDLSUSA.ORG

K Form of organization: Corporation Trust Association Other ▶

L Year of formation: 1981

M State of legal domicile:
MA

Part I Summary

1 Briefly describe the organization's mission or most significant activities:
Family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations, and help people with a diagnosis of CdLS, and others with similar characteristics, make informed decisions throughout their lives.

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)	3	13
4 Number of independent voting members of the governing body (Part VI, line 1b)	4	13
5 Total number of individuals employed in calendar year 2019 (Part V, line 2a)	5	12
6 Total number of volunteers (estimate if necessary)	6	250
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 39	7b	

	Prior Year	Current Year
8 Contributions and grants (Part VIII, line 1h)	899,379	2,188,976
9 Program service revenue (Part VIII, line 2g)		0
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	30,514	10,479
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	101,365	89,693
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,031,258	2,289,148
13 Grants and similar amounts paid (Part IX, column (A), lines 1–3)	27,570	24,447
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)	627,397	640,283
16a Professional fundraising fees (Part IX, column (A), line 11e)		0
b Total fundraising expenses (Part IX, column (D), line 25) ▶88,144		
17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	532,723	290,054
18 Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)	1,187,690	954,784
19 Revenue less expenses. Subtract line 18 from line 12	-156,432	1,334,364
	Beginning of Current Year	End of Year
20 Total assets (Part X, line 16)	999,632	2,448,230
21 Total liabilities (Part X, line 26)	24,511	17,777
22 Net assets or fund balances. Subtract line 21 from line 20	975,121	2,430,453

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: 2020-11-09
Bonnie Royster Exec. Director
Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name	Preparer's signature	Date	Check <input type="checkbox"/> if self-employed	PTIN P00063838
Firm's name ▶ Bottaro Morrill & Co LLC			Firm's EIN ▶ 06-1621300	
Firm's address ▶ 207 Pitkin Street East Hartford, CT 06108			Phone no. (860) 289-2766	

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission:

A family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome and help people with a diagnosis of CdLS, and others with similar characteristics, make informed decisions throughout their lives.

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 \$ 332,287 including grants of \$) (Revenue \$)
See Additional Data











4b (Code:) (Expenses \$ 213,536 including grants of \$) (Revenue \$)
See Additional Data

4c (Code:) (Expenses \$ 204,834 including grants of \$) (Revenue \$)
See Additional Data

4d Other program services (Describe in Schedule O.)
(Expenses \$ 26,266 including grants of \$) (Revenue \$)

4e Total program service expenses ▶ 776,923

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 	Yes	
2	Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 	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		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		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		No
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 		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 		No
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III 		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 		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 		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.		
11a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI 	Yes	
11b	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 		No
11c	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 		No
11d	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 		No
11e	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X 		No
11f	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 		No
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII 	Yes	
12b	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 		No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		No
14a	Did the organization maintain an office, employees, or agents outside of the United States?		No
14b	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		No
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		No
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		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)		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 	Yes	
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 		No
20a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H		No
20b	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? If "Yes," complete Schedule I, Parts I and II 		No

Part IV Checklist of Required Schedules (continued)

Table with 3 main columns: Question number, Question text, and Yes/No columns. Rows include questions 22 through 38 regarding organizational reporting, compensation, and tax-exempt status.

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 main columns: Question number, Question text, and Yes/No columns. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and backup withholding rules.

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

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year; 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?; 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?; 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?; 5 Did the organization become aware during the year of a significant diversion of the organization's assets?; 6 Did the organization have members or stockholders?; 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?; 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?; 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a The governing body?; 8b Each committee with authority to act on behalf of the governing body?; 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.

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 Did the organization have local chapters, branches, or affiliates?; 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?; 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?; 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; 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?; 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done; 13 Did the organization have a written whistleblower policy?; 14 Did the organization have a written document retention and destruction policy?; 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; 15b Other officers or key employees of the organization; 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?; 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?

Section C. Disclosure

Table with 3 columns: Question, Yes, No. Rows include: 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; 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;

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, 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.

(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) Morrisette Royster Executive Dir.	40.00 0.00			X				104,725	0	0
(2) Antonie Kline MD Med. Director	5.00 0.00	X						13,000	0	0
(3) Mike Feehan Treasurer	0.00 0.00	X		X				0	0	0
(4) Mike Christie Director	0.00 0.00	X						0	0	0
(5) Arthur Lander Director	0.00 0.00	X						0	0	0
(6) Emily Turner Director	0.00 0.00	X						0	0	0
(7) Eric Johnson Vice President	0.00 0.00	X		X				0	0	0
(8) Jim Kesting Director	0.00 0.00	X						0	0	0
(9) Angie Young Director	0.00 0.00	X						0	0	0
(10) Lynn Kerr MD Vice President	0.00 0.00	X		X				0	0	0
(11) Jennifer Gerton Director	0.00 0.00	X						0	0	0
(12) Dennis Drislane Director	0.00 0.00	X						0	0	0
(13) Katherina Nikzad-Terhune Secretary	0.00 0.00	X		X				0	0	0
(14) Patrick Lyons President	0.00 0.00	X		X				0	0	0

Part VIII Statement of Revenue

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

Table with 5 columns: (A) Total revenue, (B) Related or exempt function revenue, (C) Unrelated business revenue, (D) Revenue excluded from tax under sections 512 - 514. Rows include 1a-1g for Federated campaigns, membership dues, fundraising events, related organizations, government grants, and other contributions.

Table for Program Service Revenue with 6 rows (2a-f) and 5 columns (A-D). Includes Business Code column and a total line for 2a-2f.

Table for Other Revenue with 12 rows (3-12) and 5 columns (A-D). Includes sections for investment income, rental income, gain/loss from sales, fundraising events, gaming activities, and inventory sales.

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	24,447	24,447		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	0			
4 Benefits paid to or for members	0			
5 Compensation of current officers, directors, trustees, and key employees	104,726	94,670	4,235	5,821
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	477,848	431,966	19,323	26,559
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions)	0			
9 Other employee benefits	9,337	8,440	378	519
10 Payroll taxes	48,372	43,727	1,956	2,689
11 Fees for services (non-employees):				
a Management	0			
b Legal	0			
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	0			
13 Office expenses	6,676	29	6,121	526
14 Information technology	0			
15 Royalties	0			
16 Occupancy	37,786	34,386	1,511	1,889
17 Travel	0			
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0			
19 Conferences, conventions, and meetings	0			
20 Interest	0			
21 Payments to affiliates	0			
22 Depreciation, depletion, and amortization	6,158		6,158	
23 Insurance	6,712	6,068	271	373
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 PROFESSIONAL FEES	76,366	41,745	26,723	7,898
b MEETING/SEMINARS	47,030	21,754	14,281	10,995
c Printing and Publications	25,505	17,177	1,029	7,299
d Equipment rental	24,683	21,687	2,644	352
e All other expenses	59,138	30,827	5,087	23,224
25 Total functional expenses. Add lines 1 through 24e	954,784	776,923	89,717	88,144
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).				

Part X Balance Sheet

Check 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	155,846	1	308,499	
	2 Savings and temporary cash investments	62,421	2	150,080	
	3 Pledges and grants receivable, net	100,000	3	876,593	
	4 Accounts receivable, net		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		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)		6	0	
	7 Notes and loans receivable, net		7	0	
	8 Inventories for sale or use	3,659	8	3,188	
	9 Prepaid expenses and deferred charges	6,304	9	26,614	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	71,791			
	b Less: accumulated depreciation	41,237	12,625	10c	30,554
	11 Investments—publicly traded securities	657,547	11	934,580	
	12 Investments—other securities. See Part IV, line 11		12	0	
	13 Investments—program-related. See Part IV, line 11		13	0	
	14 Intangible assets		14	0	
	15 Other assets. See Part IV, line 11	1,230	15	118,122	
16 Total assets. Add lines 1 through 15 (must equal line 34)	999,632	16	2,448,230		
Liabilities	17 Accounts payable and accrued expenses	16,711	17	11,542	
	18 Grants payable		18		
	19 Deferred revenue	7,800	19	6,235	
	20 Tax-exempt bond liabilities		20		
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21		
	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		22		
	23 Secured mortgages and notes payable to unrelated third parties		23		
	24 Unsecured notes and loans payable to unrelated third parties		24		
	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		25		
	26 Total liabilities. Add lines 17 through 25	24,511	26	17,777	
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	866,717	27	1,397,281	
	28 Net assets with donor restrictions	108,404	28	1,033,172	
	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	975,121	32	2,430,453		
33 Total liabilities and net assets/fund balances	999,632	33	2,448,230		

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	2,289,148
2	Total expenses (must equal Part IX, column (A), line 25)	2	954,784
3	Revenue less expenses. Subtract line 2 from line 1	3	1,334,364
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	975,121
5	Net unrealized gains (losses) on investments	5	120,968
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	2,430,453

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 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?
- 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.

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

Additional Data

Software ID: 19009920

Software Version: 2019v5.0

EIN: 06-1057497

Name: CORNELIA DE LANGE SYNDROME FOUNDATION

Form 990 (2019)

Form 990, Part III, Line 4a:

FAMILY SUPPORT PROGRAMS

Form 990, Part III, Line 4b:

PROFESSIONAL EDUCATION OUTREACH & AWARENESS

Form 990, Part III, Line 4c:

PUBLIC INFORMATION & EDUCATION

SCHEDULE A
(Form 990 or 990-EZ)

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

Department of the Treasury
Internal Revenue Service

Name of the organization
CORNELIA DE LANGE SYNDROME FOUNDATION

Employer identification number
06-1057497

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.") . . .						
2	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf. . . .						
3	The value of services or facilities furnished by a governmental unit to the organization without charge..						
4	Total. Add lines 1 through 3						
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). . .						
6	Public support. Subtract line 5 from line 4.						

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. . .						
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources. . . .						
9	Net income from unrelated business activities, whether or not the business is regularly carried on. . .						
10	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.). . .						
11	Total support. Add lines 7 through 10						
12	Gross receipts from related activities, etc. (see instructions)					12	
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	
15	Public support percentage for 2018 Schedule A, Part II, line 14	15	
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 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.")	736,238	839,906	743,850	899,379	1,843,159	5,062,532
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	98,174	85,818	108,734	101,365	89,693	483,784
3	Gross receipts from activities that are not an unrelated trade or business under section 513						0
4	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf.						0
5	The value of services or facilities furnished by a governmental unit to the organization without charge						0
6	Total. Add lines 1 through 5	834,412	925,724	852,584	1,000,744	1,932,852	5,546,316
7a	Amounts included on lines 1, 2, and 3 received from disqualified persons						0
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.						0
c	Add lines 7a and 7b.						
8	Public support. (Subtract line 7c from line 6.)						5,546,316

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.	834,412	925,724	852,584	1,000,744	1,932,852	5,546,316
10a	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.	6,506	7,302	7,099	10,714	14,243	45,864
b	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						0
c	Add lines 10a and 10b.	6,506	7,302	7,099	10,714	14,243	45,864
11	Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on.						0
12	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						0
13	Total support. (Add lines 9, 10c, 11, and 12.)	840,918	933,026	859,683	1,011,458	1,947,095	5,592,180

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	99.180 %
16	Public support percentage from 2018 Schedule A, Part III, line 15	16	98.350 %

Section D. Computation of Investment Income Percentage

17	Investment income percentage for 2019 (line 10c, column (f) divided by line 13, column (f))	17	0.820 %
18	Investment income percentage from 2018 Schedule A, Part III, line 17	18	1.650 %

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	<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.		
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>	Yes	No
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	<input type="checkbox"/> 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: 19009920

Software Version: 2019v5.0

EIN: 06-1057497

Name: CORNELIA DE LANGE 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 D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

OMB No. 1545-0047
2019
Open to Public Inspection

▶ **Complete if the organization answered "Yes," on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.**
▶ **Attach to Form 990.**
▶ **Go to www.irs.gov/Form990 for instructions and the latest information.**

Name of the organization
CORNELIA DE LANGE SYNDROME FOUNDATION

Employer identification number
06-1057497

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.
Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? Yes No

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? Yes No

Part II Conservation Easements.
Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1 Purpose(s) of conservation easements held by the organization (check all that apply).

Preservation of land for public use (e.g., recreation or education) Preservation of an historically important land area

Protection of natural habitat Preservation of a certified historic structure

Preservation of open space

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

	Held at the End of the Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register	2d

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ _____

4 Number of states where property subject to conservation easement is located ▶ _____

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? Yes No

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ▶ _____

7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ▶ \$ _____

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? Yes No

9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.
Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenue included on Form 990, Part VIII, line 1 ▶ \$ _____

(ii) Assets included in Form 990, Part X ▶ \$ _____

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items:

a Revenue included on Form 990, Part VIII, line 1 ▶ \$ _____

b Assets included in Form 990, Part X ▶ \$ _____

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

- 3** Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
- a** Public exhibition
 - b** Scholarly research
 - c** Preservation for future generations
 - d** Loan or exchange programs
 - e** Other
- 4** Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5** During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? . . . **Yes** **No**

Part IV Escrow and Custodial Arrangements.

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a** Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? **Yes** **No**
- b** If "Yes," explain the arrangement in Part XIII and complete the following table:
- | | Amount |
|---|--------|
| 1c Beginning balance | |
| 1d Additions during the year | |
| 1e Distributions during the year | |
| 1f Ending balance | |
- 2a** Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? . . . **Yes** **No**
- b** If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

Part V Endowment Funds.

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment ▶
 - b** Permanent endowment ▶
 - c** Temporarily restricted endowment ▶
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a** Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- | | Yes | No |
|--|---------------|----|
| (i) unrelated organizations | 3a(i) | |
| (ii) related organizations | 3a(ii) | |
| b If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? | 3b | |
- 4** Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other		71,791	41,237	30,554
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).) . . . ▶				30,554

Part VII Investments—Other Securities.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other _____		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Column (b) must equal Form 990, Part X, col. (B) line 12.)		

Part VIII Investments—Program Related.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
Total. (Column (b) must equal Form 990, Part X, col.(B) line 13.)		

Part IX Other Assets.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 15.)	

Part X Other Liabilities.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

(a) Description of liability	(b) Book value
1. (1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 25.)	

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	2,437,159
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	120,968	
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d	27,043	
e	Add lines 2a through 2d			2e 148,011
3	Subtract line 2e from line 1			3 2,289,148
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1 :			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b			4c
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)			5 2,289,148

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	981,827
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a		
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d	27,043	
e	Add lines 2a through 2d			2e 27,043
3	Subtract line 2e from line 1			3 954,784
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b			4c
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)			5 954,784

Part XIII Supplemental Information

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

Return Reference	Explanation
See Additional Data Table	

Part XIII Supplemental Information *(continued)*

Return Reference	Explanation

Additional Data

Software ID: 19009920

Software Version: 2019v5.0

EIN: 06-1057497

Name: CORNELIA DE LANGE SYNDROME FOUNDATION

Supplemental Information

Return Reference	Explanation
Part XI, Line 2d: Other revenue amounts included in F/S but not included on form 990	Direct Events expenses \$27045 \$-2

Supplemental Information

Return Reference	Explanation
Part XII, Line 2d: Other expenses and losses per audited F/S	Direct Events expenses \$27045 \$-2

Part II Fundraising Events. Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

Revenue	(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
	<u>GOLF EVENTS-MO</u> (event type)	<u>GOLF EVENTS-NE</u> (event type)	(total number)	(add col. (a) through col. (c))
1 Gross receipts	74,895	41,843		116,738
2 Less: Contributions				
3 Gross income (line 1 minus line 2)	74,895	41,843		116,738
4 Cash prizes				
5 Noncash prizes				
6 Rent/facility costs				
7 Food and beverages				
8 Entertainment				
9 Other direct expenses	15,740	11,305		27,045
10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				27,045
11 Net income summary. Subtract line 10 from line 3, column (d) ▶				89,693

Part III Gaming. Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

Revenue	(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col.(a) through col.(c))
	1 Gross revenue			
2 Cash prizes				
3 Noncash prizes				
4 Rent/facility costs				
5 Other direct expenses				
6 Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	
7 Direct expense summary. Add lines 2 through 5 in column (d) ▶				
8 Net gaming income summary. Subtract line 7 from line 1, column (d) ▶				

9 Enter the state(s) in which the organization conducts gaming activities: _____

a Is the organization licensed to conduct gaming activities in each of these states? Yes No

b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes No

b If "Yes," explain: _____

- 11** Does the organization conduct gaming activities with nonmembers? Yes No
- 12** Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? Yes No
- 13** Indicate the percentage of gaming activity conducted in:
- | | | |
|--------------------------------------|------------|---|
| a The organization's facility | 13a | % |
| b An outside facility | 13b | % |

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶

Address ▶

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? Yes No

b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ _____ and the amount of gaming revenue retained by the third party ▶ \$ _____.

c If "Yes," enter name and address of the third party:

Name ▶

Address ▶

16 Gaming manager information:

Name ▶

Gaming manager compensation ▶ \$

Description of services provided ▶

- Director/officer Employee Independent contractor

17 Mandatory distributions:

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? Yes No

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____

Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

Return Reference	Explanation
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Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing.

Schedule I (Form 990)

Grants and Other Assistance to Organizations, Governments and Individuals in the United States

Complete if the organization answered "Yes," on Form 990, Part IV, line 21 or 22.

Attach to Form 990.

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

OMB No. 1545-0047

2019

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization CORNELIA DE LANGE SYNDROME FOUNDATION

Employer identification number

06-1057497

Part I General Information on Grants and Assistance

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance...
2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000.

Table with 8 columns: (a) Name and address of organization or government, (b) EIN, (c) IRC section (if applicable), (d) Amount of cash grant, (e) Amount of non-cash assistance, (f) Method of valuation, (g) Description of noncash assistance, (h) Purpose of grant or assistance. Rows 1-12.

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table.
3 Enter total number of other organizations listed in the line 1 table.

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
(1) Research	2	24,447			
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					

Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

Return Reference	Explanation
Grantmaker's Description of How Grants are Used	The Research Committee requires a report on the one-year anniversary of the grant award. The report must include budget allocation to date, a summary of research findings and information on any professional papers published or manuscripts in submission.

SCHEDULE O
(Form 990 or 990-EZ)

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

Department of the Treasury

Name of the organization

CORNELIA DE LANGE SYNDROME FOUNDATION

Employer identification number

06-1057497

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part III, Line 4d: Other Program Services Description	OTHER PROGRAM SERVICES 4: RESEARCH

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 11b: Form 990 Review Process	Review by Finance Committee and Executive Directors

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 12c: Explanation of Monitoring and Enforcement of Conflicts	Executive director and board of directors meet to review and take appropriate action to monitor and enforce the conflict of interest policy

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 15b: Compensation Review and Approval Process for Officers and Key Employees	Annual Written evaluation and leadership forms completed by officers and board members

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 19: Other Organization Documents Publicly Available	Posted on Guidestar.org, the Foundation's website CdLSUSA.org and the annual report.