

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code
(except black lung benefit trust or private foundation)

2012

Open to Public
InspectionDepartment of the Treasury
Internal Revenue Service

▶ The organization may have to use a copy of this return to satisfy state reporting requirements.

A For the 2012 calendar year, or tax year beginning , 2012, and ending**B** Check if applicable:

- ☐ Address change
☐ Name change
☐ Initial return
☐ Terminated
☐ Amended return
☐ Application pending

C
 CORNELIA DE LANGE SYNDROME FOUNDATION
 302 WEST MAIN STREET
 AVON, CT 06001

D Employer identification number

06-1057497

E Telephone number

860-676-8166

G Gross receipts \$ 1,132,277.**F** Name and address of principal officer:

SAME AS C ABOVE

H(a) Is this a group return for affiliates? ☐ Yes ☒ No**H(b)** Are all affiliates included?
If "No," attach a list. (see instructions) ☐ Yes ☐ No**I** Tax-exempt status ☒ 501(c)(3) ☐ 501(c) () (insert no.) ☐ 4947(a)(1) or ☐ 527**J** Website: WWW.CDLSUSA.ORG**H(c)** Group exemption number ▶**K** Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶**L** Year of formation: 1981**M** State of legal domicile: MA**Part I** Summary

Activities & Governance	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 <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3	Number of voting members of the governing body (Part VI, line 1a)	3	19
	4	Number of independent voting members of the governing body (Part VI, line 1b)	4	19
	5	Total number of individuals employed in calendar year 2012 (Part V, line 2a)	5	14
	6	Total number of volunteers (estimate if necessary)	6	250
	7a	Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
7b	Net unrelated business taxable income from Form 990-T, line 34	7b	0.	
Revenue	8	Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9	Program service revenue (Part VIII, line 2g)	741,415.	762,526.
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	23,021.	20,486.
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	149,523.	93,514.
	12	Total revenue — add lines 8 through 11 (must equal Part VIII, column (A), line 12)	913,959.	876,526.
	13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)	15,000.	
	14	Benefits paid to or for members (Part IX, column (A), line 4)		
Expenses	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	508,667.	457,911.
	16a	Professional fundraising fees (Part IX, column (A), line 11e)		
	b	Total fundraising expenses (Part IX, column (D), line 25) ▶	65,274.	
	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	337,037.	510,652.
	18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	860,704.	968,563.
	19	Revenue less expenses. Subtract line 18 from line 12	53,255.	-92,037.
	Net Assets or Fund Balances	20	Total assets (Part X, line 16)	Beginning of Current Year
21		Total liabilities (Part X, line 26)	946,676.	886,638.
22		Net assets or fund balances. Subtract line 21 from line 20	26,046.	19,228.
			920,630.	867,410.

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

MARIE CONCKLIN-MALLOY

EXECUTIVE DIREC

Type or print name and title.

Paid
Preparer
Use Only

Print/Type preparer's name

Preparer's signature

Date

Check ☐ if
self-employed

PTIN

DOUGLAS MORRILL, CPA

DOUGLAS MORRILL, CPA

6/17/13

P00063838

Firm's name ▶ BOTTARO, MORRILL & CO., LLC

Firm's address ▶ 207 PITKIN STREET

EAST HARTFORD, CT 06108

Firm's EIN ▶ 06-1621300

Phone no. 860-289-2766

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

☒ Yes☐ No

BAA For Paperwork Reduction Act Notice, see the separate instructions.

TEEA0113L 12/18/12

Form 990 (2012)

Part III Statement of Program Service AccomplishmentsCheck if Schedule O contains a response to any question in this Part III. ☒ **X**

- 1 Briefly describe the organization's mission:

SEE SCHEDULE O

- 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 and section 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4 a (Code:) (Expenses \$ 376,893. including grants of \$) (Revenue \$)FAMILY SUPPORT PROGRAMS4 b (Code:) (Expenses \$ 274,907. including grants of \$) (Revenue \$)PUBLIC INFORMATION & EDUCATION4 c (Code:) (Expenses \$ 185,756. including grants of \$) (Revenue \$)PROFESSIONAL EDUCATION OUTREACH & AWARENESS4 d Other program services. (Describe in Schedule O.) SEE SCHEDULE O(Expenses \$ 12,573. including grants of \$) (Revenue \$)4 e Total program service expenses 850,129.

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	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If 'Yes,' complete Schedule C, Part I		X
4 Section 501(c)(3) organizations Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If 'Yes,' complete Schedule C, Part II		X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If 'Yes,' complete Schedule C, Part III		X
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		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas or historic structures? If 'Yes,' complete Schedule D, Part II		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If 'Yes,' complete Schedule D, Part III		X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management credit repair, or debt negotiation services? If 'Yes,' complete Schedule D, Part IV		X
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		X
11 If the organization's answer to any of the following questions is 'Yes,' then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a Did the organization report an amount for land, buildings and equipment in Part X, line 10? If 'Yes,' complete Schedule D, Part VI	X	
b Did the organization report an amount for investments — other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VII		X
c Did the organization report an amount for investments — program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VIII		X
d Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part IX		X
e Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If 'Yes,' complete Schedule D, Part X		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? If 'Yes,' complete Schedule D, Parts XI, and XII	X	
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.		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If 'Yes,' complete Schedule F, Parts I and IV		X
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the United States? If 'Yes,' complete Schedule F, Parts II and IV		X
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the United States? If 'Yes,' complete Schedule F, Parts III and IV		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If 'Yes,' complete Schedule G, Part I (see instructions)		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If 'Yes,' complete Schedule G, Part II	X	
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		X
20a Did the organization operate one or more hospital facilities? If 'Yes,' complete Schedule H		X
b If 'Yes' to line 20a, did the organization attach a copy of its audited financial statements to this return?		

Part IV Checklist of Required Schedules (continued)

		Yes	No
21	Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? If 'Yes,' complete Schedule I, Parts I and II.		X
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? If 'Yes,' complete Schedule I, Parts I and III.		X
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? If 'Yes,' complete Schedule J.		X
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, and that was issued after December 31, 2002? If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No,' go to line 25.		X
24b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
24c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
24d	Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?		
25a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If 'Yes,' complete Schedule L, Part I.		X
25b	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? If 'Yes,' complete Schedule L, Part I.		X
26	Was a loan to or by a current or former officer, director, trustee, key employee, highest compensated employee, or disqualified person outstanding as of the end of the organization's tax year? If 'Yes,' complete Schedule L, Part II.		X
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? If 'Yes,' complete Schedule L, Part III.		X
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):		
28a	a A current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L, Part IV.		X
28b	b A family member of a current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L, Part IV.		X
28c	c An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? If 'Yes,' complete Schedule L, Part IV.		X
29	Did the organization receive more than \$25,000 in non-cash contributions? If 'Yes,' complete Schedule M.		X
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If 'Yes,' complete Schedule M.		X
31	Did the organization liquidate, terminate, or dissolve and cease operations? If 'Yes,' complete Schedule N, Part I.		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If 'Yes,' complete Schedule N, Part II.		X
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? If 'Yes,' complete Schedule R, Part I.		X
34	Was the organization related to any tax-exempt or taxable entity? If 'Yes,' complete Schedule R, Parts II, III, IV, and V, line 1.		X
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
35b	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)? If 'Yes,' complete Schedule R, Part V, line 2.		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If 'Yes,' complete Schedule R, Part V, line 2.		X
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? If 'Yes,' complete Schedule R, Part VI.		X
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.	X	

BAA

Form 990 (2012)

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

		Yes	No
1 a Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable.	1 a 4		
b Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.	1 b 0		
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1 c		X
2 a 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.	2 a 14		
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2 b	X	
Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. (see instructions)			
3 a Did the organization have unrelated business gross income of \$1,000 or more during the year?	3 a		X
b If 'Yes' has it filed a Form 990-T for this year? If 'No,' provide an explanation in Schedule O.	3 b		
4 a 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)?	4 a		X
b If 'Yes,' enter the name of the foreign country: See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.			
5 a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5 a		X
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5 b		X
c If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?	5 c		
6 a 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?	6 a		X
b If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6 b		
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?	7 a		X
b If 'Yes,' did the organization notify the donor of the value of the goods or services provided?	7 b		
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7 c		X
d If 'Yes,' indicate the number of Forms 8282 filed during the year.	7 d		
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7 e		X
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7 f		X
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7 g		
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7 h		
8 Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?	8		
9 Sponsoring organizations maintaining donor advised funds.			
a Did the organization make any taxable distributions under section 4966?	9 a		
b Did the organization make a distribution to a donor, donor advisor, or related person?	9 b		
10 Section 501(c)(7) organizations. Enter:			
a Initiation fees and capital contributions included on Part VIII, line 12.	10 a		
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.	10 b		
11 Section 501(c)(12) organizations. Enter:			
a Gross income from members or shareholders.	11 a		
b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)	11 b		
12 a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12 a		
b If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year.	12 b		
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?	13 a		
Note. See the instructions for additional information the organization must report on Schedule O.			
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.	13 b		
c Enter the amount of reserves on hand.	13 c		
14 a Did the organization receive any payments for indoor tanning services during the tax year?	14 a		X
b If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O.	14 b		

Part VI Governance, Management and Disclosure For each 'Yes' response to lines 2 through 7b below, and for a 'No' response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.Check if Schedule O contains a response to any question in this Part VI. ☒ **X****Section A. Governing Body and Management**

	Yes	No
1 a Enter the number of voting members of the governing body at the end of the tax year. 1 a 19 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.		
b Enter the number of voting members included in line 1a, above, who are independent 1 b 19		
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		X
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		X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? 4		X
5 Did the organization become aware during the year of a significant diversion of the organization's assets? 5		X
6 Did the organization have members or stockholders? 6		X
7 a 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? 7 a		X
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or other persons other than the governing body? 7 b		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a The governing body? 8 a	X	
b Each committee with authority to act on behalf of the governing body? 8 b	X	
9 Is there any officer, director or 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		X

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

	Yes	No
10 a Did the organization have local chapters, branches, or affiliates? 10 a		X
b 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? 10 b		
11 a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11 a	X	
b Describe in Schedule O the process, if any, used by the organization to review this Form 990. SEE SCHEDULE O		
12 a Did the organization have a written conflict of interest policy? If 'No,' go to line 13 12 a	X	
b Were officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12 b	X	
c Did the organization regularly and consistently monitor and enforce compliance with the policy? If 'Yes,' describe in Schedule O how this is done. SEE SCHEDULE O 12 c	X	
13 Did the organization have a written whistleblower policy? 13	X	
14 Did the organization have a written document retention and destruction policy? 14	X	
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?		
a The organization's CEO, Executive Director, or top management official 15 a	X	
b Other officers of key employees of the organization. SEE SCHEDULE O 15 b	X	
If 'Yes' to line 15a or 15b, describe the process in Schedule O. (See instructions.)		
16 a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? 16 a		X
b 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 taken steps to safeguard the organization's exempt status with respect to such arrangements? 16 b		

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed ► **NONE**

18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make 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 makes its governing documents, conflict of interest policy, and financial statements available to the public during the tax year. SEE SCHEDULE O

20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization:

► **MARIE CONCKLIN-MALLOY 302 WEST MAIN ST. AVON CT 06001 860-676-8166**

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck if Schedule O contains a response to any question in this Part VII. ☐**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees****1 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, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

☐ 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) MICHELE CHURCHMAN DIRECTOR	0	X						0.	0.	0.
(2) DAVID BARNES DIRECTOR	0	X						0.	0.	0.
(3) CATHERINE CARON DIRECTOR	0	X						0.	0.	0.
(4) MICHELE CHAMPION DIRECTOR	0	X						0.	0.	0.
(5) EILEEN AHEARN, M.D. VICE PRESIDENT	0	X		X				0.	0.	0.
(6) ROBERT BONEBERG, ESQ. VICE PRESIDENT	0	X		X				0.	0.	0.
(7) DIANNE LESSA DIRECTOR	0	X						0.	0.	0.
(8) GARTH BLACK SECRETARY	0	X		X				0.	0.	0.
(9) CARLOS MADRID, ESQ. DIRECTOR	0	X						0.	0.	0.
(10) PENNY KETCHEM DIRECTOR	0	X						0.	0.	0.
(11) KARI CUNNINGHAM ROSVIK, VICE PRESIDENT	0	X		X				0.	0.	0.
(12) DAVID HARVEY DIRECTOR	0	X						0.	0.	0.
(13) MARC NEEDLMAN PRESIDENT	0	X		X				0.	0.	0.
(14) THOMAS O'BRIEN TREASURER	0	X		X				0.	0.	0.

Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (cont)

(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			
(15) MARY OPITZ DIRECTOR	0	X						0.	0.	0.
(16) FRAN RISSLAND DIRECTOR	0	X						0.	0.	0.
(17) BETH SMISLOFF DIRECTOR	0	X						0.	0.	0.
(18) RICHARD HAALAND DIRECTOR	0	X						0.	0.	0.
(19) WENDY MILLER DIRECTOR	0	X						0.	0.	0.
(20) MARIE CONCKLIN-MALLOY EXECUTIVE DIREC	40 0			X				81,158.	0.	0.
(21)										
(22)										
(23)										
(24)										
(25)										
1 b Sub-total								81,158.	0.	0.
c Total from continuation sheets to Part VII, Section A								0.	0.	0.
d Total (add lines 1b and 1c)								81,158.	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**

3 Did the organization list any **former** officer, director or trustee, key employee, or highest compensated employee on line 1a? If 'Yes,' complete Schedule J for such individual.

	Yes	No
3		X
4		X
5		X

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? If 'Yes' complete Schedule J for such individual.

5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If 'Yes,' complete Schedule J for such person.

Section B. Independent Contractors

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

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

Part VIII Statement of RevenueCheck if Schedule O contains a response to any question 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, 513, or 514
CONTRIBUTIONS, GIFTS, GRANTS AND OTHER SIMILAR AMOUNTS	1 a Federated campaigns.	1 a			
	b Membership dues.	1 b			
	c Fundraising events.	1 c	324,281.		
	d Related organizations.	1 d			
	e Government grants (contributions).	1 e			
	f All other contributions, gifts, grants, and similar amounts not included above.	1 f	438,245.		
	g Noncash contributions included in lns 1a-1f: \$				
	h Total. Add lines 1a-1f.		762,526.		
PROGRAM SERVICE REVENUE	Business Code				
	2 a				
	b				
	c				
	d				
	e				
	f All other program service revenue.				
	g Total. Add lines 2a-2f.				
OTHER REVENUE	3 Investment income (including dividends, interest and other similar amounts).		10,217.		10,217.
	4 Income from investment of tax-exempt bond proceeds.				
	5 Royalties.				
	(i) Real (ii) Personal				
	6 a Gross rents.				
	b Less: rental expenses.				
	c Rental income or (loss).				
	d Net rental income or (loss).				
	(i) Securities (ii) Other				
	7 a Gross amount from sales of assets other than inventory.		219,953.		
	b Less: cost or other basis and sales expenses.		209,684.		
	c Gain or (loss).		10,269.		
	d Net gain or (loss).		10,269.	10,269.	
	8 a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18.	a	139,581.		
	b Less: direct expenses.	b	46,067.		
	c Net income or (loss) from fundraising events.		93,514.		93,514.
	9 a Gross income from gaming activities. See Part IV, line 19.	a			
	b Less: direct expenses.	b			
	c Net income or (loss) from gaming activities.				
	10 a Gross sales of inventory, less returns and allowances.	a			
b Less: cost of goods sold.	b				
c Net income or (loss) from sales of inventory.					
Miscellaneous Revenue Business Code					
11 a					
b					
c					
d All other revenue.					
e Total. Add lines 11a-11d.					
12 Total revenue. See instructions.		876,526.	10,269.	0.	103,731.

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 to any question 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 governments and organizations in the United States. See Part IV, line 21.				
2 Grants and other assistance to individuals in the United States. See Part IV, line 22.				
3 Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16.				
4 Benefits paid to or for members.				
5 Compensation of current officers, directors, trustees, and key employees.	81,158.	72,231.	3,246.	5,681.
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.	0.	0.	0.
7 Other salaries and wages.	337,395.	297,688.	13,174.	26,533.
8 Pension plan accruals and contributions (include section 401(k) and section 403(b) employer contributions).				
9 Other employee benefits.				
10 Payroll taxes.	39,358.	35,029.	1,574.	2,755.
11 Fees for services (non-employees):				
a Management.				
b Legal.				
c Accounting.				
d Lobbying.				
e Professional fundraising services. See Part IV, line 17.				
f Investment management fees.				
g Other. (If line 11g amt exceeds 10% of line 25, column (A) amt, list line 11g expenses on Sch O).	14,262.	12,693.	571.	998.
12 Advertising and promotion.				
13 Office expenses.	17,574.	12,944.	3,675.	955.
14 Information technology.				
15 Royalties.				
16 Occupancy.	33,975.	31,937.	1,019.	1,019.
17 Travel.				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials.				
19 Conferences, conventions, and meetings.				
20 Interest.				
21 Payments to affiliates.				
22 Depreciation, depletion, and amortization.	12,978.		12,978.	
23 Insurance.	4,639.	4,305.	144.	190.
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 MEETING/SEMINARS	229,479.	217,517.	3,722.	8,240.
b PROFESSIONAL FEES	69,166.	62,360.	4,508.	2,298.
c PUBLIC RELATIONS	29,437.	26,718.	906.	1,813.
d PRINTING AND PUBLICATIONS	27,750.	23,915.	1,260.	2,575.
e All other expenses	71,392.	52,792.	6,383.	12,217.
25 Total functional expenses. Add lines 1 through 24e.	968,563.	850,129.	53,160.	65,274.
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 SheetCheck if Schedule O contains a response to any question in this Part X. ☐

		(A) Beginning of year		(B) End of year
ASSETS	1 Cash — non-interest-bearing	135,494.	1	151,629.
	2 Savings and temporary cash investments	247,141.	2	199,665.
	3 Pledges and grants receivable, net		3	
	4 Accounts receivable, net		4	
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions). Complete Part II of Schedule L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges		9	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 149,161.		
	b Less: accumulated depreciation	10b 123,433.	32,235.	10c 25,728.
	11 Investments — publicly traded securities	530,576.	11	508,386.
	12 Investments — other securities. See Part IV, line 11.		12	
	13 Investments — program-related. See Part IV, line 11.		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11.	1,230.	15	1,230.
16 Total assets. Add lines 1 through 15 (must equal line 34)	946,676.	16	886,638.	
LIABILITIES	17 Accounts payable and accrued expenses	26,046.	17	19,228.
	18 Grants payable		18	
	19 Deferred revenue		19	
	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 current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		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	26,046.	26	19,228.
NET ASSETS OR FUND BALANCES	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets	890,310.	27	820,804.
	28 Temporarily restricted net assets	30,320.	28	46,606.
	29 Permanently restricted net assets		29	
	Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.			
	30 Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building, or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
	33 Total net assets or fund balances	920,630.	33	867,410.
34 Total liabilities and net assets/fund balances	946,676.	34	886,638.	

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Form 990 (2012)

Part XI Reconciliation of Net AssetsCheck if Schedule O contains a response to any question in this Part XI. ☐

1	Total revenue (must equal Part VIII, column (A), line 12)	1	876,526.
2	Total expenses (must equal Part IX, column (A), line 25)	2	968,563.
3	Revenue less expenses. Subtract line 2 from line 1	3	-92,037.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	920,630.
5	Net unrealized gains (losses) on investments	5	38,817.
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	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	867,410.

Part XII Financial Statements and ReportingCheck if Schedule O contains a response to any question in this Part XII. ☐

	Yes	No
1 Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> 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?		X
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:		
<input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		
2b Were the organization's financial statements audited by an independent accountant?	X	
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:		
<input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		
2c 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?	X	
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?		X
3b 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		

BAA

Form 990 (2012)

SCHEDULE A
(Form 990 or 990-EZ)

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. ► See separate instructions.

OMB No. 1545-0047

2012

Open to Public Inspection

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 11, 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.)
- 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 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.)
- 10 ☐ An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 11 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or 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 that describes the type of supporting organization and complete lines 11e through 11h.
- a ☐ Type I b ☐ Type II c ☐ Type III – Functionally integrated d ☐ Type III – Non-functionally integrated
- e ☐ By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f If the organization received a written determination from the IRS that is a Type I, Type II or Type III supporting organization, check this box ☐
- g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

- (i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?
- (ii) A family member of a person described in (i) above?
- (iii) A 35% controlled entity of a person described in (i) or (ii) above?

	Yes	No
11 g (i)		
11 g (ii)		
11 g (iii)		

h Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section (see instructions))	(iv) Is the organization in column (i) listed in your governing document?		(v) Did you notify the organization in column (i) of your support?		(vi) Is the organization in column (i) organized in the U.S.?		(vii) Amount of monetary support
			Yes	No	Yes	No	Yes	No	
(A)									
(B)									
(C)									
(D)									
(E)									
Total									

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

Schedule A (Form 990 or 990-EZ) 2012

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants'.)						
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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(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 IV.)						
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 2012 (line 6, column (f) divided by line 11, column (f)).	14	%
15 Public support percentage from 2011 Schedule A, Part II, line 14.	15	%
16a 33-1/3% support test – 2012. If the organization did not check the box on line 13, and the 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 – 2011. 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 – 2012. 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 IV 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 – 2011. 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 IV 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 9 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 yr beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions and membership fees received. (Do not include any 'unusual grants'.)	805,331.	849,687.	1,085,087.	741,415.	762,526.	4,244,046.
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.			95,439.	149,523.	93,514.	338,476.
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.	805,331.	849,687.	1,180,526.	890,938.	856,040.	4,582,522.
7a Amounts included on lines 1, 2, and 3 received from disqualified persons.	0.	0.	0.	0.	0.	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.	0.	0.	0.	0.	0.
c Add lines 7a and 7b.	0.	0.	0.	0.	0.	0.
8 Public support. (Subtract line 7c from line 6.)						4,582,522.

Section B. Total Support

Calendar year (or fiscal yr beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
9 Amounts from line 6.	805,331.	849,687.	1,180,526.	890,938.	856,040.	4,582,522.
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.	13,942.	5,508.	28,932.	23,021.	20,486.	91,889.
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						0.
c Add lines 10a and 10b.	13,942.	5,508.	28,932.	23,021.	20,486.	91,889.
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 IV.)						0.
13 Total support. (Add lines 9, 10c, 11, and 12.)	819,273.	855,195.	1,209,458.	913,959.	876,526.	4,674,411.
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						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

15 Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f)).	15	98.03 %
16 Public support percentage from 2011 Schedule A, Part III, line 15.	16	97.95 %

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f)).	17	1.97 %
18 Investment income percentage from 2011 Schedule A, Part III, line 17.	18	2.05 %

- 19a **33-1/3% support tests — 2012.** 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 — 2011.** 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

Part IV **Supplemental Information.** Complete this part to provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Also complete this part for any additional information. (See instructions).

[illegible]

Schedule B
(Form 990, 990-EZ,
or 990-PF)

Department of the Treasury
Internal Revenue Service

Schedule of Contributors

► **Attach to Form 990, Form 990-EZ, or Form 990-PF**

OMB No. 1545-0047

2012

Name of the organization

CORNELIA DE LANGE SYNDROME FOUNDATION

Employer identification number

06-1057497

Organization type (check one):

Filers of:

Form 990 or 990-EZ

Section:

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

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

☐ 527 political organization

Form 990-PF

☐ 501(c)(3) exempt private foundation

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

☐ 501(c)(3) taxable private foundation

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

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

General Rule

☒ For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, \$5,000 or more (in money or property) from any one contributor. (Complete Parts I and II.)

Special Rules

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

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

☐ For a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions for use *exclusively* for religious, charitable, etc., purposes, but these contributions did not total to more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Do not complete any of the parts unless the **General Rule** applies to this organization because it received nonexclusively religious, charitable, etc., contributions of \$5,000 or more during the year. ► \$ _____

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

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

Schedule B (Form 990, 990-EZ, or 990-PF) (2012)

**SCHEDULE D
(Form 990)**Department of the Treasury
Internal Revenue Service

Name of the organization

Supplemental Financial Statements

▶ **Complete if the organization answered 'Yes,' to Form 990, Part IV, lines 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.**
▶ **Attach to Form 990.** ▶ **See separate instructions.**

OMB No. 1545-0047

2012**Open to Public
Inspection**

Employer identification number

CORNELIA DE LANGE SYNDROME FOUNDATION

06-1057497

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

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year.....		
2 Aggregate contributions to (during year).....		
3 Aggregate 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?.....	<input type="checkbox"/> Yes	<input type="checkbox"/> 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?.....	<input type="checkbox"/> Yes	<input type="checkbox"/> No

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

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

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or education)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> 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 Tax Year
a Total number of conservation easements.....	2 a
b Total acreage restricted by conservation easements.....	2 b
c Number of conservation easements on a certified historic structure included in (a).....	2 c
d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register.....	2 d

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, and enforcing conservation easements during the year ▶

7 Amount of expenses incurred in monitoring, inspecting, 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' to Form 990, Part IV, line 8.

1 a 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) Revenues included in 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 Revenues included in 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' to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1 a 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
1 c Beginning balance	
1 d Additions during the year	
1 e Distributions during the year	
1 f Ending balance	

2 a Did the organization include an amount on Form 990, Part X, line 21? ☐ 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' to Form 990, Part IV, line 10.

	(a) Current	(b) Prior year	(c) Two years	(d) Three years	(e) Four years
1 a 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 in lines 2a, 2b, and 2c should equal 100%.

3 a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

- (i) unrelated organizations ☐ 3a(i) Yes No
 (ii) related organizations ☐ 3a(ii) Yes No

b If 'Yes' to 3a(ii), are the related organizations listed as required on Schedule R? ☐ 3b Yes No

4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment. 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
1 a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other	149,161.		123,433.	25,728.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				25,728.

BAA

Schedule D (Form 990) 2012

Part VII Investments – Other Securities. See Form 990, Part X, line 12. N/A

(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)		
(I)		
Total. (Column (b) must equal Form 990, Part X, column (B) line 12.) ... ▶		

Part VIII Investments – Program Related. See Form 990, Part X, line 13. N/A

(a) Description of investment type	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
Total. (Column (b) must equal Form 990, Part X, column (B) line 13.) ... ▶		

Part IX Other Assets. See Form 990, Part X, line 15. N/A

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, column (B), line 15.) ... ▶	

Part X Other Liabilities. See Form 990, Part X, line 25.

(a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
Total. (Column (b) must equal Form 990, Part X, column (B) line 25.) ... ▶	

2. FIN 48 (ASC 740) Footnote. 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

Reconciliation of Revenue per Audited Financial Statements With Revenue per Return			1	966,640.
1	Total revenue, gains, and other support per audited financial statements			
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains on investments	2a	38,817.	
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c	5,230.	
d	Other (Describe in Part XIII.) . . . SEE PART XIII	2d	46,067.	
e	Add lines 2a through 2d		2e	90,114.
3	Subtract line 2e from line 1.		3	876,526.
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	876,526.

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

Reconciliation of Expenses per Audited Financial Statements With Expenses per Return		1	1,014,630.
1	Total expenses and losses per audited financial statements		
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.) SEE PART XIII	2d	46,067.
e	Add lines 2a through 2d	2e	46,067.
3	Subtract line 2e from line 1.	3	968,563.
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	968,563.

Part XIII Supplemental Information

Complete this part to 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.

BAA

2012

SCHEDULE D, PART XIII - SUPPLEMENTAL INFORMATION PAGE 5

CORNELIA DE LANGE SYNDROME FOUNDATION

06-1057497

SCHEDULE D, PART XI, LINE 2D

OTHER REVENUE INCLUDED IN F/S BUT NOT INCLUDED ON FORM 990

DIRECT EVENTS EXPENSES.....	\$	46,067.
TOTAL	\$	<u>46,067.</u>

SCHEDULE D, PART XII, LINE 2D

OTHER EXPENSES AND LOSSES PER AUDITED F/S

DIRECT EVENTS EXPENSES.....	\$	46,067.
TOTAL	\$	<u>46,067.</u>

Department of the Treasury
Internal Revenue Service

Complete if the organization answered 'Yes' to Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.
▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No. 1545-0047

2012

Open to Public Inspection

Name of the organization

CORNELIA DE LANGE SYNDROME FOUNDATION

Employer identification number

06-1057497

Part I Fundraising Activities. Complete if the organization answered "Yes" to Form 990, Part IV, line 17.
Form 990-EZ filers are not required to complete this part.

- 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- a ☒ Mail solicitations
- b ☒ Internet and email solicitations
- c ☐ Phone solicitations
- d ☐ In-person solicitations
- e ☒ Solicitation of non-government grants
- f ☐ Solicitation of government grants
- g ☒ Special fundraising events

- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? ☐ Yes ☒ No

- b** If 'Yes,' list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in column (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
Total						0

- 3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

Part II Fundraising Events. Complete if the organization answered 'Yes' to 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 GOLF EVENTS-NE (event type)	(b) Event #2 GOLF EVENTS-MO (event type)	(c) Other events 2 (total number)	(d) Total events (add column (a) through column (c))
	1 Gross receipts	64,387.	42,820.	32,374.	139,581.
	2 Less: Charitable contributions				
	3 Gross income (line 1 minus line 2)	64,387.	42,820.	32,374.	139,581.
DIRECT EXPENSES	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages				
	8 Entertainment				
	9 Other direct expenses	25,656.	11,860.	8,551.	46,067.
	10 Direct expense summary. Add lines 4 through 9 in column (d).				46,067.
	11 Net income summary. Combine line 3, column (d), and line 10.				93,514.

Part III Gaming. Complete if the organization answered 'Yes' to 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 column (a) through column (c))
	1 Gross revenue				
DIRECT EXPENSES	2 Cash prizes				
	3 Non-cash 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. Combine lines 1, column (d) and line 7.				

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

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

b If 'No,' explain: _____

10 a 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 operate gaming activities with nonmembers? | <input type="checkbox"/> Yes | <input type="checkbox"/> 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? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

- | | | | |
|--|-----------------------------------|------|---|
| 13 Indicate the percentage of gaming activity operated in: | | | |
| a | The organization's facility | 13 a | % |
| b | An outside facility | 13 b | % |

- 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 contact 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 to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____

Part IV **Supplemental Information.** Complete this part to 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 complete this part to provide any additional information (see instructions).

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

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.

OMB No. 1545-0047

2012

Open to Public
Inspection

Name of the organization

CORNELIA DE LANGE SYNDROME FOUNDATION

Employer identification number

06-1057497

FORM 990, PART III, LINE 1 - ORGANIZATION 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.

FORM 990, PART III, LINE 4D - OTHER PROGRAM SERVICES DESCRIPTION

RESEARCH

FORM 990, PART VI, LINE 11B - FORM 990 REVIEW PROCESS

REVIEW BY FINANCE COMMITTEE AND EXECUTIVE DIRECTORS

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

FORM 990, PART VI, LINE 15B - COMPENSATION REVIEW & APPROVAL PROCESS - OFFICERS & KEY EMPLOYEES

ANNUAL WRITTEN EVALUATION AND LEADERSHIP FORMS COMPLETED BY OFFICERS AND BOARD
MEMBERS

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.