

**Return of Organization Exempt From Income Tax**

OMB No. 1545-0047

**2010**

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

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

Department of the Treasury  
Internal Revenue Service

**A** For the **2010** calendar year, or tax year beginning **2010**, and ending **2010**

**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

**F** Name and address of principal officer:  
SAME AS C ABOVE

**G** Gross receipts \$ **1,535,201.**

**H(a)** Is this a group return for affiliates?  Yes  No  
**H(b)** Are all affiliates included?  Yes  No  
 If "No," attach a list. (see instructions)

**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

**Summary**

**1** Briefly describe the organization's mission or most significant activities: 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

**2** Check this box  if the organization discontinued its operations or disposed of more than 25% of its net assets.

<b>3</b> Number of voting members of the governing body (Part VI, line 1a)	3	12
<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)	4	12
<b>5</b> Total number of individuals employed in calendar year 2010 (Part V, line 2a)	5	9
<b>6</b> Total number of volunteers (estimate if necessary)	6	250
<b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
<b>7b</b> Net unrelated business taxable income from Form 990-T, line 34	7b	0.

	Prior Year	Current Year
<b>8</b> Contributions and grants (Part VIII, line 1h)	534,733.	1,085,087.
<b>9</b> Program service revenue (Part VIII, line 2g)		
<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)	-115,471.	29,340.
<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	314,954.	95,439.
<b>12</b> Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	734,216.	1,209,866.
<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)	30,000.	
<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)		
<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	409,333.	504,845.
<b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e)		
<b>16b</b> Total fundraising expenses (Part IX, column (D), line 25)	65,319.	
<b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24f)	272,063.	545,028.
<b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	711,396.	1,049,873.
<b>19</b> Revenue less expenses. Subtract line 18 from line 12	22,820.	159,993.
<b>20</b> Total assets (Part X, line 16)	Beginning of Current Year 760,238.	End of Year 933,030.
<b>21</b> Total liabilities (Part X, line 26)	21,297.	19,098.
<b>22</b> Net assets or fund balances. Subtract line 21 from line 20	738,941.	913,932.

**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: Liana Freshon Date: 5/13/11

Type or print name and title: LIANA FRESHON Executive Director

**Paid Preparer Use Only**

Print/preparer's name: DOUGLAS MORRILL, CPA Preparer's signature: DOUGLAS MORRILL, CPA Date: 5/13/11 Check  self-employed  PPTN 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

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

Part III Statement of Program Service Accomplishments

Check 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 [X] No

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

4 Describe the exempt purpose achievements for each of the organization's three largest program services 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.

4a (Code: [ ]) (Expenses \$ 362,303. including grants of \$ [ ]) (Revenue \$ [ ]) FAMILY SUPPORT PROGRAMS

4b (Code: [ ]) (Expenses \$ 301,619. including grants of \$ [ ]) (Revenue \$ [ ]) PUBLIC INFORMATION & EDUCATION

4c (Code: [ ]) (Expenses \$ 255,492. including grants of \$ [ ]) (Revenue \$ [ ]) PROFESSIONAL EDUCATION OUTREACH & AWARENESS

4d Other program services. (Describe in Schedule O.) SEE SCHEDULE O (Expenses \$ 19,631. including grants of \$ [ ]) (Revenue \$ [ ])

4e Total program service expenses ▶ 939,045.

**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		
6 Did the organization maintain any donor advised funds or any similar funds or accounts where 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; 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 term, permanent, 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, XII, and XIII	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, XII, and XIII 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, and program service activities outside the United States? 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
20 a Did the organization operate one or more hospitals? If 'Yes,' complete Schedule H		X
b If 'Yes' to line 20a, did the organization attach its audited financial statements to this return? Note. Some Form 990 filers that operate one or more hospitals must attach audited financial statements (see instructions)		

**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
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?.....		
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?.....		
d 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
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If 'Yes,' complete Schedule L, Part I.....		X
26 Was a loan to or by a current or former officer, director, trustee, key employee, highly 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 a grant selection committee member, or to a person related to such an individual? 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):		
a A current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L, Part IV.....		X
b A family member of a current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L, Part IV.....		X
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
35 Is any related organization a controlled entity within the meaning of section 512(b)(13)?.....		X
a 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..... <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
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 11 and 19? Note. All Form 990 filers are required to complete Schedule O.....	X	

BAA

**Part V** Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response to any question in this Part V.

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable. <input type="text" value="6"/>		
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable. <input type="text" value="0"/>		
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? <input type="checkbox"/>		X
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return. <input type="text" value="9"/>		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? <input type="checkbox"/>	X	
<i>Note.</i> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. (see instructions)			
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year? <input type="checkbox"/>		X
b	If 'Yes,' has it filed a Form 990-T for this year? If 'No,' provide an explanation in Schedule O. <input type="checkbox"/>		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)? <input type="checkbox"/>		X
b If 'Yes,' enter the name of the foreign country: <input type="text" value="See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts."/>			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? <input type="checkbox"/>		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? <input type="checkbox"/>		X
c	If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T? <input type="checkbox"/>		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible? <input type="checkbox"/>		X
b	If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? <input type="checkbox"/>		
<b>7 Organizations that may receive deductible contributions under section 170(c).</b>			
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? <input type="checkbox"/>		X
b	If 'Yes,' did the organization notify the donor of the value of the goods or services provided? <input type="checkbox"/>		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? <input type="checkbox"/>		X
d	If 'Yes,' indicate the number of Forms 8282 filed during the year. <input type="text" value="7d"/>		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? <input type="checkbox"/>		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? <input type="checkbox"/>		X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? <input type="checkbox"/>		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? <input type="checkbox"/>		
<b>8 Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations.</b> Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year? <input type="checkbox"/>			
<b>9 Sponsoring organizations maintaining donor advised funds.</b>			
a	Did the organization make any taxable distributions under section 4966? <input type="checkbox"/>		
b	Did the organization make a distribution to a donor, donor advisor, or related person? <input type="checkbox"/>		
<b>10 Section 501(c)(7) organizations.</b> Enter:			
a	Initiation fees and capital contributions included on Part VIII, line 12. <input type="text" value="10a"/>		
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities. <input type="text" value="10b"/>		
<b>11 Section 501(c)(12) organizations.</b> Enter:			
a	Gross income from members or shareholders. <input type="text" value="11a"/>		
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.). <input type="text" value="11b"/>		
<b>12a Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041? <input type="checkbox"/>			
b	If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year. <input type="text" value="12b"/>		
<b>13 Section 501(c)(29) qualified nonprofit health insurance issuers.</b>			
a	Is the organization licensed to issue qualified health plans in more than one state? <input type="checkbox"/>		
<i>Note.</i> 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. <input type="text" value="13b"/>		
c	Enter the amount of reserves on hand. <input type="text" value="13c"/>		
<b>14a</b> Did the organization receive any payments for indoor tanning services during the tax year? <input type="checkbox"/>			
b If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O. <input type="checkbox"/>			

**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
1a Enter the number of voting members of the governing body at the end of the tax year. ....	1a	12
b Enter the number of voting members included in line 1a, above, who are independent. ....	1b	12
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 Does the organization have members or stockholders? .....	6	X
7a Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body? .....	7a	X
b Are any decisions of the governing body subject to approval by members, stockholders, or other persons? .....	7b	X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a The governing body? .....	8a	X
b Each committee with authority to act on behalf of the governing body? .....	8b	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
10a Does the organization have local chapters, branches, or affiliates? .....	10a	X
b If 'Yes,' does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization? .....	10b	
11a Has the organization provided a copy of this Form 990 to all members of its governing body before filing the form? .....	11a	X
b Describe in Schedule O the process, if any, used by the organization to review this Form 990. SEE SCHEDULE O		
12a Does the organization have a written conflict of interest policy? If 'No,' go to line 13. ....	12a	X
b Are officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts? .....	12b	X
c Does 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	12c	X
13 Does the organization have a written whistleblower policy? .....	13	X
14 Does 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. ....	15a	X
b Other officers of key employees of the organization. SEE SCHEDULE O. ....	15b	X
If 'Yes' to line 15a or 15b, describe the process in Schedule O. (See instructions.)		
16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? .....	16a	X
b If 'Yes,' has the organization adopted 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? .....	16b	

**Section C. Disclosure**

- 17 List the states with which a copy of this Form 990 is required to be filed ▶ SEE SCHEDULE O
- 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
- 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. SEE SCHEDULE O
- 20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization:  
 ▶ LIANA GARCIA-FRESHER 302 WEST MAIN ST. AVON CT 06001

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

Check 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 (describe hours for related organizations in Schedule O)	(C) Position (check all that apply)						(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) GLENN DIXON VICE PRESIDENT	0						0.	0.	0.	
(2) ROBERT BONEBERG, ESQ. DIRECTOR	0						0.	0.	0.	
(3) DAVID HARVEY DIRECTOR	0						0.	0.	0.	
(4) MARC NEEDLMAN DIRECTOR	0						0.	0.	0.	
(5) PAUL PATITUCCI TREASURER	0	X		X			0.	0.	0.	
(6) DAVE VILAND VICE PRESIDENT	0	X		X			0.	0.	0.	
(7) DAVID FOWLER PRESIDENT	0	X		X			0.	0.	0.	
(8) EILEEN AHEARN, M.D. DIRECTOR	0	X					0.	0.	0.	
(9) DALE DORSETT, PH.D. DIRECTOR	0	X					0.	0.	0.	
(10) GARTH BLACK DIRECTOR	0	X					0.	0.	0.	
(11) ELIZABETH FOUTS, PH.D. DIRECTOR	0	X					0.	0.	0.	
(12) PENNY KETCHEM DIRECTOR	0	X					0.	0.	0.	
(13) KARI CUNNINGHAM ROSVIK, DIRECTOR	0	X					0.	0.	0.	
(14) LIANA GARCIA-FRESHER EXECUTIVE DIREC	40				X		114,200.	0.	0.	
(15) -----										
(16) -----										
(17) -----										

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

(A) Name and title	(B) Average hours per week (describe hours for related organizations in Sch O)	(C) Position (check all that apply)					(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			
(18) -----									
(19) -----									
(20) -----									
(21) -----									
(22) -----									
(23) -----									
(24) -----									
(25) -----									
(26) -----									
(27) -----									
(28) -----									
(29) -----									
<b>1 b Sub-total</b> .....						114,200.	0.	0.	
<b>c Total from continuation sheets to Part VII, Section A</b> .....						0.	0.	0.	
<b>d Total (add lines 1b and 1c)</b> .....						114,200.	0.	0.	

**2** Total number of individuals (including but not limited to those listed above) who received more than \$100,000 in reportable compensation from the organization ▶ 1

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

**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.

(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

**Statement of Revenue**

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514	
<b>CONTRIBUTIONS, GIFTS, GRANTS AND OTHER SIMILAR AMOUNTS</b>	1 a Federated campaigns	1 a				
	b Membership dues	1 b				
	c Fundraising events	1 c	312,315.			
	d Related organizations	1 d				
	e Government grants (contributions)	1 e	220,393.			
	f All other contributions, gifts, grants, and similar amounts not included above	1 f	552,379.			
	g Noncash contributions included in lns 1a-1f: \$					
	<b>h Total. Add lines 1a-1f.</b>		<b>1,085,087.</b>			
<b>PROGRAM SERVICE REVENUE</b>	2 a	Business Code				
	b					
	c					
	d					
	e					
	f All other program service revenue					
	<b>g Total. Add lines 2a-2f.</b>					
<b>OTHER REVENUE</b>	3 Investment income (including dividends, interest and other similar amounts)		13,529.		13,529.	
	4 Income from investment of tax-exempt bond proceeds					
	5 Royalties					
	6 a Gross Rents	(i) Real				
		(ii) Personal				
		b Less: rental expenses				
		c Rental income or (loss)				
	d Net rental income or (loss)					
	7 a Gross amount from sales of assets other than inventory	(i) Securities	341,146.			
		(ii) Other				
		b Less: cost or other basis and sales expenses	325,335.			
		c Gain or (loss)	15,811.			
	d Net gain or (loss)		15,811.		15,811.	
	8 a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18.	a	95,439.			
		b Less: direct expenses				
c Net income or (loss) from fundraising events			95,439.		95,439.	
9 a Gross income from gaming activities. See Part IV, line 19.	a					
	b Less: direct expenses					
	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					
	c Net income or (loss) from sales of inventory					
<b>Miscellaneous Revenue</b>		<b>Business Code</b>				
11 a						
b						
c						
d All other revenue						
e Total. Add lines 11a-11d						
<b>12 Total revenue. See instructions.</b>		<b>1,209,866.</b>	<b>0.</b>	<b>0.</b>	<b>124,779.</b>	

**Part D Statement of Functional Expenses**

Section 501(c)(3) and 501(c)(4) organizations must complete all columns.  
All other organizations must complete column (A) but are not required to complete columns (B), (C), and (D).

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 U.S. See Part IV, line 21				
2 Grants and other assistance to individuals in the U.S. See Part IV, line 22				
3 Grants and other assistance to governments, organizations, and individuals outside the U.S. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	114,200.	102,780.	4,568.	6,852.
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	351,382.	321,293.	11,531.	18,558.
8 Pension plan contributions (include section 401(k) and section 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes	39,263.	35,336.	1,571.	2,356.
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				
12 Advertising and promotion				
13 Office expenses	24,299.	18,650.	3,327.	2,322.
14 Information technology				
15 Royalties				
16 Occupancy	33,598.	31,582.	1,008.	1,008.
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	50,880.	45,792.	1,526.	3,562.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	8,385.		8,385.	
23 Insurance	4,902.	4,549.	152.	201.
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24f. If line 24f amount exceeds 10% of line 25, column (A) amount, list line 24f expenses on Schedule O.)				
a MEETING/SEMINARS	216,789.	206,008.	2,342.	8,439.
b PROFESSIONAL FEES	81,336.	76,454.	2,994.	1,888.
c POSTAGE AND SHIPPING	43,570.	33,871.	2,182.	7,517.
d PRINTING AND PUBLICATIONS	36,932.	26,009.	2,845.	8,078.
e DUES & SUBSCRIPTIONS	22,446.	20,296.	900.	1,250.
f All other expenses	21,891.	16,425.	2,178.	3,288.
<b>25 Total functional expenses. Add lines 1 through 24f</b>	<b>1,049,873.</b>	<b>939,045.</b>	<b>45,509.</b>	<b>65,319.</b>
26 Joint costs. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720). Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

**Part X Balance Sheet**

		(A) Beginning of year		(B) End of year
ASSETS	1 Cash – non-interest-bearing.....	310,479.	1	191,911.
	2 Savings and temporary cash investments.....	30,316.	2	162,889.
	3 Pledges and grants receivable, net.....		3	
	4 Accounts receivable, net.....		4	
	5 Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L.....		5	
	6 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).....		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 120,244.			
b Less: accumulated depreciation.....	10b 98,345.	22,887.	10c	21,899.
11 Investments – publicly traded securities.....	395,326.	11	555,101.	
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 <b>Total assets.</b> Add lines 1 through 15 (must equal line 34).....	760,238.	16	933,030.	
LIABILITIES	17 Accounts payable and accrued expenses.....	21,297.	17	19,098.
	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 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. Complete Part X of Schedule D.....		25	
	26 <b>Total liabilities.</b> Add lines 17 through 25.....	21,297.	26	19,098.
NET ASSETS OR FUND BALANCES	<b>Organizations that follow SFAS 117, check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27 through 29 and lines 33 and 34.</b>			
	27 Unrestricted net assets.....	715,454.	27	913,932.
	28 Temporarily restricted net assets.....	23,487.	28	
	29 Permanently restricted net assets.....		29	
	<b>Organizations that do not follow SFAS 117, check here</b> <input type="checkbox"/> <b>and complete lines 30 through 34.</b>			
	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 <b>Total net assets or fund balances.</b> .....	738,941.	33	913,932.	
34 <b>Total liabilities and net assets/fund balances.</b> .....	760,238.	34	933,030.	

BAA

**Part XI Reconciliation of Net Assets**

Check 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	1,209,866.
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,049,873.
3	Revenue less expenses. Subtract line 2 from line 1	3	159,993.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	738,941.
5	Other changes in net assets or fund balances (explain in Schedule O). SEE SCHEDULE O	5	14,998.
6	Net assets or fund balances at end of year. Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))	6	913,932.

**Part XII Financial Statements and Reporting**

Check 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
2b	Were the organization's financial statements audited by an independent accountant?	X	
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? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.	X	
2d	If 'Yes' to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued 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		
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 (2010)

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

**Public Charity Status and Public Support**

OMB No. 1545-0047

**2010**

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.

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 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 — Other
- 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?

	Yes	No
(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?.....	<input type="checkbox"/>	<input type="checkbox"/>
(ii) A family member of a person described in (i) above?.....	<input type="checkbox"/>	<input type="checkbox"/>
(iii) A 35% controlled entity of a person described in (i) or (ii) above?.....	<input type="checkbox"/>	<input type="checkbox"/>

**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 support
			Yes	No	Yes	No	Yes	No	
(A)									
(B)									
(C)									
(D)									
(E)									
<b>Total</b>									

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

Schedule A (Form 990 or 990-EZ) 2010

**Part III 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) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include 'unusual grants'.)						
2 Tax revenues levied for the organization's benefit and either paid to it 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) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(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 2010 (line 6, column (f) divided by line 11, column (f)).	14	%
15 Public support percentage from 2009 Schedule A, Part II, line 14.	15	%
16a 33-1/3% support test – 2010. 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 – 2009. 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 – 2010. 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 – 2009. 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) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total
1 Gifts, grants, contributions and membership fees received. (Do not include any 'unusual grants'.)	872,157.	736,307.	805,331.	849,687.	1,085,087.	4,348,569.
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.	95,439.
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.	872,157.	736,307.	805,331.	849,687.	1,180,526.	4,444,008.
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.)						4,444,008.

**Section B. Total Support**

Calendar year (or fiscal yr beginning in) ▶	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total
9 Amounts from line 6.	872,157.	736,307.	805,331.	849,687.	1,180,526.	4,444,008.
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.	20,914.	21,784.	13,942.	5,508.	28,932.	91,080.
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						0.
c Add lines 10a and 10b.	20,914.	21,784.	13,942.	5,508.	28,932.	91,080.
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 lns 9, 10c, 11, and 12.)	893,071.	758,091.	819,273.	855,195.	1,209,458.	4,535,088.

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 2010 (line 8, column (f) divided by line 13, column (f)).	15	98.0 %
16 Public support percentage from 2009 Schedule A, Part III, line 15.	16	98.3 %

**Section D. Computation of Investment Income Percentage**

17 Investment income percentage for 2010 (line 10c, column (f) divided by line 13, column (f)).	17	2.0 %
18 Investment income percentage from 2009 Schedule A, Part III, line 17.	18	1.7 %

19a 33-1/3% support tests – 2010. 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 – 2009. 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.



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

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

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

OMB No. 1545-0047

**2010**

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, aggregate 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 aggregate 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 their Form 990, or check the box on line H of its Form 990-EZ, or on 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, 990-EZ, or 990-PF.**

**Schedule B (Form 990, 990-EZ, or 990-PF) (2010)**

**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, 11, or 12.  
▶ Attach to Form 990. ▶ See separate instructions.

OMB No. 1545-0047

**2010**

Employer identification number

06-1057497

CORNELIA DE LANGE SYNDROME FOUNDATION

**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 .....	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 8/17/06, 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, 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 XIV, 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.

- 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 XIV, 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 XIV.

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 organization answered 'Yes' to 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 XIV and complete the following table:

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

2a Did the organization include an amount on Form 990, Part X, line 21?  Yes  No

b If 'Yes,' explain the arrangement in Part XIV.

**Part V Endowment Funds.** Complete if the organization answered 'Yes' to 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 year end balance held as:

- a Board designated or quasi-endowment  %
- b Permanent endowment  %
- c Term endowment  %

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' to 3a(ii), are the related organizations listed as required on Schedule R?	3b	

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

**Part VI Land, Buildings, and Equipment.** See Form 990, Part X, line 10.

Description of investment	(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	120,244.		98,345.	21,899.
<b>Total.</b> Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				21,899.

BAA

**Part VI 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) -----		
<b>Total.</b> (Column (b) must equal Form 990 Part X, column (B) line 12.)		

**Part VII 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)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, column (B) line 13.)		

**Part VIII 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)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, column (B), line 15)	

**Part IX Other Liabilities.** (See Form 990, Part X, line 25)

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

2. FIN 48 (ASC 740) Footnote. In Part XIV, 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).

**Part III Reconciliation of Change in Net Assets from Form 990 to Audited Financial Statements**

1	Total revenue (Form 990, Part VIII, column (A), line 12)		1,209,866.
2	Total expenses (Form 990, Part IX, column (A), line 25)		1,049,873.
3	Excess or (deficit) for the year. Subtract line 2 from line 1		159,993.
4	Net unrealized gains (losses) on investments		14,998.
5	Donated services and use of facilities		
6	Investment expenses		
7	Prior period adjustments		
8	Other (Describe in Part XIV)		
9	Total adjustments (net). Add lines 4 through 8		14,998.
10	Excess or (deficit) for the year per audited financial statements. Combine lines 3 and 9		174,991.

**Part IV Reconciliation of Revenue per Audited Financial Statements With Revenue per Return**

1	Total revenue, gains, and other support per audited financial statements	1	1,248,351.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
	a Net unrealized gains on investments	2a	14,998.
	b Donated services and use of facilities	2b	
	c Recoveries of prior year grants	2c	23,487.
	d Other (Describe in Part XIV)	2d	
	e Add lines 2a through 2d	2e	38,485.
3	Subtract line 2e from line 1	3	1,209,866.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
	a Investments expenses not included on Form 990, Part VIII, line 7b	4a	
	b Other (Describe in Part XIV)	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	1,209,866.

**Part V Reconciliation of Expenses per Audited Financial Statements With Expenses per Return**

1	Total expenses and losses per audited financial statements	1	1,049,873.
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 XIV)	2d	
	e Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	1,049,873.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
	a Investments expenses not included on Form 990, Part VIII, line 7b	4a	
	b Other (Describe in Part XIV)	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	1,049,873.

**Part XIV 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, line 8; Part XII, lines 2d and 4b; and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

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

**Supplemental Information Regarding Fundraising or Gaming Activities**

OMB No. 1545-0047

**2010**

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.

Name of the organization

Employer identification number

**CORNELIA DE LANGE SYNDROME FOUNDATION**

**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						
<b>Total</b>						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.

AL AK AZ CA CO CT FL GA IL KS KY LA ME MD ME MA MI MN MS MO NH NJ NM NY NC ND OH  
OK OR PA RI SC TN UT VA WV WI WA

**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 6a. List events with gross receipts greater than \$5,000.

REVENUE		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		GOLF EVENTS-NE (event type)	GOLF EVENTS-HO (event type)	(total number)	(add column (a) through column (c))
	1	59,814.	35,625.		95,439.
	2				
	3	59,814.	35,625.		95,439.
DIRECT EXPENSES	4				
	5				
	6				
	7				
	8				
	9				
	10	Direct expense summary. Add lines 4- through 9 in column (d).....▶			
11	Net income summary. Combine line 3, column (d), and line 10.....▶				95,439.

**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				
EXPENSES DIRECT	2				
	3				
	4				
	5				
	6	<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: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

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 operate 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 operated 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 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).

\_\_\_\_\_

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\_\_\_\_\_

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

**Supplemental Information to Form 990 or 990-EZ**

OMB No. 1545-0047

**2010**

Department of the Treasury  
Internal Revenue Service

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.

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 LIFETIMES.

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

RESEARCH

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

REVIEW BY BOARD 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 FOR OFFICERS & KEY EMPLOYEE**

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

**FORM 990, PART VI, LINE 17 - LIST OF STATES WHICH THIS RETURN IS FILED**

AL AK AZ AR CA CO CT FL GA IL KS KY LA ME MD MA MI MN MS MO NH NJ NM NY NC ND OH  
OK OR PA RI SC TN UT VA WA WV WI

**FORM 990, PART VI, LINE 19 - OTHER ORGANIZATION DOCUMENTS PUBLICLY AVAILABLE**

POSTED ON GUIDESTAR.ORG WEBSITE OR UPON REQUEST

FORM 990, PART XI, LINE 5  
OTHER CHANGES IN NET ASSETS OR FUND BALANCES

NET UNREALIZED GAINS OR LOSSES ON INVESTMENTS.....	\$	14,998.
TOTAL	\$	<u>14,998.</u>