Form	99	0
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(Rev. January 2020)

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations) Do not enter social security numbers on this form as it may be made public.
 Go to www.irs.gov/Form990 for instructions and the latest information.

Open to Public Inspection

OMB No. 1545-0047

2019

Dep Inte	artment of th rnal Revenue	ne Treasury e Service	•	Do not en Go to www.	ter social security irs.gov/Form990	/ numbers on t for instructi	his form as it ons and th	t may be mad ne latest inf	le public. formation	1.		Inspection	
A		2019 calenda			-			and ending					
B	Check if ap		-	,	9		,,		,	D Employ	er identi	, ification number	
			ORNELTA I	DE LANG	E SYNDROM	E FOUNDA	TON			06-	1057	497	
		change 3	0 TOWER 1	LANE #4						E Telepho		-	
	Initial	יא	VON, CT (06001						860	-676	-8166	
		urn/terminated								000	010	0100	
		ded return								G Gross r	eceipts	\$ 232	9,442.
			Name and addr	ess of principal	officer: BONN	רד םרעכיד	ירס	ŀ	H(a) Is this a	a group retur			1 37
		S	AME AS C	ABOVE	DONN	LE ROISI	LIN	ŀ	H(b) Are all	subordinates	included	d? Ye	
Ι	Tax-exer		501(c)(3)	501(c) () < (inser	rt no.) 4	947(a)(1) or	527	If "INO,"	attach a list	. (see ins	structions)	
J	Websi		CDLSUSA.		, <u>,</u>	,	()()		H(c) Group e	exemption nu	umber 🕨	•	
Κ	Form of o		Corporation	Trust	Association	Other ►	LY	ear of formatio	n: 1981	L M s	State of l	egal domicile: N	IA
Pa	art I	Summary											
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a	E				ID ACCURAT								
anc	<u>C</u> 2				S, AND HEI								<u>.{S</u>
Governance	<u>W</u> .				TICS, MAKE								
Sov	2 Ch 3 Nu	eck this box			n discontinued ning body (Pa						net as	sets.	13
~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~	<b>4</b> Nu				s of the govern						4		13
ties	5 To			-	calendar year						5		12
Activities &	6 To	tal number of	volunteers (	estimate if	necessary)	· · · · · · · · · · · · · · · ·					6		250
Ac					Part VIII, colum						7a		0.
	<b>b</b> Ne	t unrelated bi	usiness taxab	le income	from Form 990	-T, line 39.					7b		0.
	0 00	utvikutione ev	ad avanta (Da	سلالا	1					rior Year		Current	
e	<ul> <li>8 Contributions and grants (Part VIII, line 1h)</li> <li>9 Program service revenue (Part VIII, line 2g)</li> </ul>									899,3	579.	2,18	8,976.
Revenue	9 FIG	-	-		A), lines 3, 4, a					30,5	11	1	0,479.
Re	11 Ot		•		nes 5, 6d, 8c, 9					101,3			<u>0,479.</u> 9,693.
		-			(must equal Pa		-			,031,2			9,148.
				-	X, column (A),					27,5			4,447.
	<b>14</b> Be	nefits paid to	or for memb	ers (Part IX	(, column (A),	line 4)							
	<b>15</b> Sa	laries, other o	compensatior	n, employee	e benefits (Parl	t IX, column	(A), lines	5-10)		627,3	397.	64	0,283.
Expenses	<b>16a</b> Pro	ofessional fur	ndraising fees	(Part IX, c	olumn (A), line	e 11e)							
per	<b>b</b> To	tal fundraisin	a expenses (l	Part IX, col	umn (D), line 2	25) ►	8	8,144.					
й	17 Ot				nes 11a-11d, 1			,		532,7	23	29	0,054.
					equal Part IX, o	-				,187,6			4,784.
					8 from line 12.				-	-156,4			4,364.
þ	e P		•							g of Currer		End of	
Assets	<b>20</b> To									<u> </u>		2,44	8,230.
	3	tal liabilities (	Part X, line 2	26)						24,5	511.	1	7,777.
Net Set	<b>22</b> Ne	t assets or fu	nd balances.	Subtract lin	ne 21 from line	e 20				975,1	.21.	2,43	0,453.
Pa	art II	Signature	Block						·				
Und	ler penalties	of perjury, I decla	re that I have exa	mined this retu	rn, including accom all information of wh	panying schedu	les and statem	nents, and to th	ne best of m	y knowledge	and beli	ef, it is true, corr	ect, and
COIL	ipiete. Decial		(other than onice	r) is based off a		lich preparer na	s ally knowled	iye.					
~		Signature of	of officer						Dat	Þ			
SI	gn ere			Л									
пе	re		E ROYSTE nt name and title	R					EXEC.	DIRE	TOR		
		Print/Type prep			Preparer's signatu	ire		Date		Chook	if	PTIN	
~	: d		MORRILL	עםט	DOUGLAS N		CPA			Check self-employ		P0006383	8
	nid Teparer	Firm's name			RILL & CO.		UL V	I		Sensempioy	Ju	10000303	0
	se Only	Firm's address	► 207 PI							Firm's FIN	► ∩ ⊆.	-1621300	
		1 mm s address		IARTFORI		18				Phone no.		-289-276	6
Ma	v the IRS	discuss this			shown above?		ctions)						No
	-				he separate in		,		A0101L 01/2				<b>990</b> (2019)

Form	n 990 (2019) CORNELIA DE LANGE SYNDROME FOUNDATION	06-1057497	Page 2
Par			
	Check if Schedule O contains a response or note to any line in this Part III	<u> </u>	Х
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		
2	Form 990 or 990-EZ?		V No
	If "Yes," describe these new services on Schedule O.	Yes	X No
3	Did the organization cease conducting, or make significant changes in how it conducts, any program servi		V No
3	If "Yes," describe these changes on Schedule O.	ices? Yes	X No
4	Describe the organization's program service accomplishments for each of its three largest program service	oc as massured by	avpapsas
4	Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations and revenue, if any, for each program service reported.	to others, the total	expenses,
4 a	a (Code: ) (Expenses \$ 332,287. including grants of \$ ) (Rev	venue \$	)
	FAMILY SUPPORT PROGRAMS	· · · ·	/
11	b (Code: ) (Expenses \$ 213,536. including grants of \$ ) (Rev	venue \$	)
41	PROFESSIONAL EDUCATION OUTREACH & AWARENESS		)
	FROPESSIONAL EDUCATION OUTREACH & AWARENESS		
4 0	c (Code: ) (Expenses \$ 204,834. including grants of \$ ) (Rev	venue \$	)
	PUBLIC INFORMATION & EDUCATION		
1.	d Other program services (Describe on Schedule O.) SEE SCHEDULE O		
40	(Expenses \$ 26,266. including grants of \$ ) (Revenue \$		)
4	e Total program service expenses ► 776,923.		,
BAA		For	m <b>990</b> (2019)

# Form 990 (2019) CORNELIA DE LANGE SYNDROME FOUNDATION Part IV Checklist of Required Schedules

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

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 Form 990 (2019)
 CORNELIA DE LANGE SYNDROME FOUNDATION

 Part IV
 Checklist of Required Schedules (continued)

			Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If 'Yes,' complete Schedule I, Parts I and III.	22	Х	
23	Did the organization answer 'Yes' to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If 'Yes,' complete Schedule J</i> .	23		Х
24	a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No, 'go to line 25a</i>	24a		Х
I	b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
	c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
	d Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?	24d		
25	a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If 'Yes,' complete Schedule L, Part I	25a		Х
l	<b>b</b> Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If 'Yes,' complete Schedule L, Part I</i> .	25b		Х
26	Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If 'Yes,' complete Schedule L, Part II</i>	26		Х
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If 'Yes,' complete Schedule L, Part III.</i>	27		Х
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):			
	<b>a</b> A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If</i> 'Yes,' complete Schedule L, Part IV	28a		Х
I	<b>b</b> A family member of any individual described in line 28a? <i>If 'Yes,' complete Schedule L, Part IV</i>	28b		Х
	c A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If Yes,' complete Schedule L, Part IV	28c		Х
29	Did the organization receive more than \$25,000 in non-cash contributions? If 'Yes,' complete Schedule M	29		Х
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If 'Yes,' complete Schedule M</i>	30		Х
31	Did the organization liquidate, terminate, or dissolve and cease operations? If 'Yes,' complete Schedule N, Part I	31		Х
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If 'Yes,' complete Schedule N, Part II.	32		Х
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	33		Х
	Was the organization related to any tax-exempt or taxable entity? If 'Yes,' complete Schedule R, Part II, III, or IV, and Part V, line 1	34		Х
35	a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		Х
	<b>b</b> If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If 'Yes,' complete Schedule R, Part V, line 2</i>	35b		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If 'Yes,' complete Schedule R, Part V, line 2	36		Х
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If 'Yes,' complete Schedule R, Part VI</i>	37		Х
	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O	38	Х	
Pa	rt V Statements Regarding Other IRS Filings and Tax Compliance			
	Check if Schedule O contains a response or note to any line in this Part V		Yes	· No
	a Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable1 a13b Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable1 b0		103	
	c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1 c	Х	
BAA		Form	990 (	2019

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)			
		1	
		Yes	No
2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax State- ments, filed for the calendar year ending with or within the year covered by this return 2a 12			
<b>b</b> If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2 b	Х	
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		Х
<b>b</b> If 'Yes,' has it filed a Form 990-T for this year? If 'No' to line 3b, provide an explanation on Schedule 0	3 b		
<b>4 a</b> 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		Х
b If 'Yes,' enter the name of the foreign country►	_		
See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).			V
<b>5a</b> Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		X X
<b>b</b> Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5 b		
c If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?	5 c		<u> </u>
<b>6 a</b> 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		Х
<b>b</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	_		X
services provided to the payor?	7 a 7 b		
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file	70		<u> </u>
Form 8282?	7 c		Х
d If 'Yes,' indicate the number of Forms 8282 filed during the year 7d			
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7 e		Х
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7 f		Х
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7 g		
<b>h</b> 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. Did a donor advised fund maintained by the sponsoring			
organization have excess business holdings at any time during the year?	8		
9 Sponsoring organizations maintaining donor advised funds.	0.0		
<ul> <li>a Did the sponsoring organization make any taxable distributions under section 4966?</li> <li>b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?</li> </ul>			<u> </u>
10 Section 501(c)(7) organizations. Enter:	90		
a Initiation fees and capital contributions included on Part VIII, line 12			
<b>b</b> Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities <b>10b</b>	-		
11 Section 501(c)(12) organizations. Enter:	-		
a Gross income from members or shareholders			
<b>b</b> Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)			
12 a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		
<b>b</b> If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year	120		
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?	13a		
Note: See the instructions for additional information the organization must report on Schedule O.			
<b>b</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			
c Enter the amount of reserves on hand			
14a Did the organization receive any payments for indoor tanning services during the tax year?	14a		Х
<b>b</b> If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation on Schedule O	14b		
15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year?	15		Х
If 'Yes,' see instructions and file Form 4720, Schedule N.			
16 Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If 'Yes,' complete Form 4720, Schedule O.	16		X

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

Check if Schedule O	contains a	rochonco	or noto to	2011	lino i	n thic	Dart 1/1	
	contains a	response		ally	iiiie i	11 11 11 15	Part VI.	

Sec	ction 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 13 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 on Schedule O.			
	<b>b</b> Enter the number of voting members included on line 1a, above, who are independent <b>1b</b>			
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		Х
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person?	3		Х
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		Х
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5		Х
6	Did the organization have members or stockholders?	6		Х
	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		Х
I	b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7 b		Х
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	Х	
	b Each committee with authority to act on behalf of the governing body?	8 b	Х	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? <i>If 'Yes,' provide the names and addresses on Schedule Q</i>			Х
500	ction B. Policies (This Section B requests information about policies not required by the Internal Re	9		
Sec	<b>LIGH B. POILCIES</b> (This Section B requests information about policies not required by the internal Re	:vent	Yes	· · · · ·
10	a Did the organization have local chapters, branches, or affiliates?	10 a	Tes	No X
	<b>b</b> If 'Yes,' did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their	IUa		Л
	operations are consistent with the organization's exempt purposes?	10 b		
11 a	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	Х	
I	b Describe in Schedule O the process, if any, used by the organization to review this Form 990. SEE SCHEDULE O			
	a Did the organization have a written conflict of interest policy? If 'No,' go to line 13	12a	Х	
I	b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Х	
(	c Did the organization regularly and consistently monitor and enforce compliance with the policy? <i>If 'Yes,' describe in Schedule O how this was done</i> SEESCHEDULE.Q	12 c	Х	
13	Did the organization have a written whistleblower policy?	13	Х	
14	Did the organization have a written document retention and destruction policy?	14	Х	
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?			
i	a The organization's CEO, Executive Director, or top management official	15 a	Х	
I	b Other officers or key employees of the organizationSEE .SCHEDULE.O	15b	Х	
	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		Х
I	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 take steps to safeguard the organization's exempt status with respect to such arrangements?	16 b		
Ser	tion C. Disclosure	100		
17	List the states with which a copy of this Form 990 is required to be filed ► <u>SEE_SCHEDULE_O</u>			
18	Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (Section 5) available for public inspection. Indicate how you made these available. Check all that apply.			ıly)
	X       Own website       Another's website       Upon request       Other (explain on Schedule O)			
19	Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements availate the public during the tax year. SEE SCHEDULE O	ble to		
20	State the name, address, and telephone number of the person who possesses the organization's books and records ►			

20	otate the name, a		icprioric		or the p		10 00330.	5505 1	ne organi	2010113 00013	
	MORRISETTE	ROYSTER	302	WEST	MAIN	ST.	AVON	СТ	06001	860-676-	8166

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06-1057497

Form 990 (2019) CORNELIA DE LANGE SYNDROME FOUNDATION	06-1057497	Page <b>7</b>
Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Independent Contractors	t Compensated Employe	es, and
Check if Schedule O contains a response or note to any line in this Part VII	·····	
Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensa	ted Employees	
a Complete this table for all persons required to be listed. Report compensation for the calendar year ending organization's tax year.	with or within the	
• List all of the organization's current officers, directors, trustees (whether individuals or organizat	ions) regardless of amount of	

лy compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.

• List all of the organization's current key employees, if any. See instructions for definition of 'key employee.'

• List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.

• List all of the organization's former officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.

• List all of the organization's former directors or trustees that received, in the capacity as a former director or trustee of the

organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See instructions for the order in which to list the persons above.

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

			(C)							
	(A) Name and title	<b>(B)</b> Average hours			<b>(D)</b> Reportable compensation from	<b>(E)</b> Reportable compensation from	<b>(F)</b> Estimated amount			
		liburs per week (list any hours for related organiza- tions below dotted line)	Individual trustee or director			Highest compensated	Former	(W-2/1099-MISC)	(W-2/1099-MISC)	of other compensation from the organization and related organizations
(1)	MORRISETTE ROYSTER	40								
	EXECUTIVE DIR.	0			Х			104,725.	0.	0.
_(2)	ANTONIE KLINE M.D.	5	v					12 000	0	0
(2)	MED. DIRECTOR	0	Х					13,000.	0.	0.
_(3)	MIKE FEEHAN	0	Х		х			0.	0.	0.
(4)	MIKE CHRISTIE	0	Λ		Λ			0.	0.	0.
	DIRECTOR	0	Х					0.	0.	0.
(5)	ARTHUR LANDER	0						0.		<u> </u>
_`_'_	DIRECTOR		Х					0.	0.	0.
(6)	EMILY TURNER	0								
	DIRECTOR	0	Х					0.	0.	0.
(7)	ERIC_JOHNSON	0								
	VICE PRESIDENT	0	Х		Х			0.	0.	0.
(8)	JIM_KESTING	0								
	DIRECTOR	0	Х					0.	0.	0.
(9)	ANGIE YOUNG	0								
	DIRECTOR	0	Х					0.	0.	0.
(10)	LYNN KERR M.D.	0								
	VICE PRESIDENT	0	Х		Х			0.	0.	0.
(11)	JENNIFER_GERTON	0						_		_
	DIRECTOR	0	Х					0.	0.	0.
(12)	DENNIS DRISLANE	0						0	0	0
(1.2)	DIRECTOR	0	Х					0.	0.	0.
(13)	KATHERINA NIKZAD-TERHUNE	0	v		v			0	0	^
(1.1)	SECRETARY	0	Х		Х			0.	0.	0.
(14)	PATRICK LYONS PRESIDENT	0	Х		х			0.	0.	0
BAA	LVEOIDENI	U TEEA0						0.	υ.	0 . Form <b>990</b> (2019)
DAA		ILLAU	IU/L	0//31/	19					1 01111 <b>330</b> (2019)

#### Form 990 (2019) CORNELIA DE LANGE SYNDROME FOUNDATION

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Part VII Section A. Officers, Directors, Tru	ustees,	Key l	Emp	oloy	ees,	and	d Highest Com	pensated Emp	loyees (continued)
	(B)			(C)					
(A) Name and title	Average hours per week	box.	unless	perso	n re than n is bot ctor/trus	h an stee)	<b>(D)</b> Reportable compensation from	(E) Reportable compensation from	<b>(F)</b> Estimated amount of other
	(list any hours	Indiv or di	Institutio	Ney Ney	Hight empl	Forn	the organization (W-2/1099-MISC)	related organizations (W-2/1099-MISC)	compensation from the organization
	for related organiza	ndividual trustee or director	nstitutional trustee	Key employee	employee	ner			and related organizations
	- tions below dotted	truste	al trus	yee	mpen				
	line)	ě	lee		sated				
(15)									
(16)									
(17)									
(18)									
(19)									
(20)									
(21)									
(22)									
(23)									
 (24)									
		·							
(25)									
1 b Subtotal		· · · · · ·				•	117,725.	0.	0.
c Total from continuation sheets to Part VII, Secti						•	0.	0.	0.
d Total (add lines 1b and 1c) 2 Total number of individuals (including but not limited						ved	117,725.	0. O of reportable comm	0.
from the organization > 1		noted t	10010	) 1110		vcu			
									Yes No
3 Did the organization list any former officer, direct on line 1a? If 'Yes,' complete Schedule J for successful and the second secon	tor, truste <i>h individu</i>	ee, key <i>Jal</i>	y em	ploye	e, or	high	nest compensated	employee	. <b>3</b> X
4 For any individual listed on line 1a, is the sum on the organization and related organizations greated organizations greated organizations and the sum of the sum o	er than \$1	50,00	0? If	'Yes	,' con	nple	te Schedule J for		. <b>4</b> X
<ul><li><i>such individual</i></li><li>Did any person listed on line 1a receive or accru</li></ul>	e comper	nsatior	ר fror	n anv	/ unre	late	d organization or	individual	
for services rendered to the organization? If 'Yes	s," comple	ete Sci	neau	eJt	or suc	cn p	erson		. <b>5</b> X
<ol> <li>Complete this table for your five highest compen- compensation from the organization. Report comper</li> </ol>	sated ind	epend the ca	lent o Ilenda	ontra ir yea	actors ir endi	tha	t received more th vith or within the or	han \$100,000 of ganization's tax year	r.
(A) Name and business add							<b>(B)</b> Description of		<b>(C)</b> Compensation
2 Total number of independent contractors (including l	out not lim	ited to	those	e liste	ed aho	ve)	who received more	than	
\$100,000 of compensation from the organization						,			

## Form 990 (2019) CORNELIA DE LANGE SYNDROME FOUNDATION

## Part VIII Statement of Revenue

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1 <b>u</b> i	Check if Schedule O contains a response	e or note to any	/ line in this Part V			
			<b>(A)</b> Total revenue	<b>(B)</b> Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
nts nts	1 a Federated campaigns   1 a					
Contributions, Gifts, Grants and Other Similar Amounts	b Membership dues 1b					
ts, ( Am	c Fundraising events 1c	284,385.				
Gif ilar	d Related organizations 1d					
ns, Sim	e Government grants (contributions) 1 e f All other contributions, gifts, grants, and					
utio er S		,904,591.				
oth	a Noncash contributions included in	, , , , , , , , , , , , , , , , , , , ,				
ont	lines 1a-1f	•	0 100 076			
		usiness Code	2,188,976.			
enn	2a					
Program Service Revenue	b					
ice	c					
Serv	d					
m m	е					
ogra	f All other program service revenue					
Pro	g Total. Add lines 2a-2f	•••••				
	3 Investment income (including dividends, intere	est, and				
	other similar amounts)		14,243.			14,243.
	<ul><li>4 Income from investment of tax-exempt bon</li><li>5 Royalties</li></ul>					
	(i) Real	(ii) Personal				
	6a Gross rents	()				
	b Less: rental expenses 6b					
	c Rental income or (loss) 6c					
	d Net rental income or (loss)					
	7 a Gross amount from (i) Securities	(ii) Other				
	sales of assets					
	b Less: cost or other basis					
	and sales expenses <b>7b</b> 10,403.	2,846.				
	<b>c</b> Gain or (loss) <b>7c</b> -918.	-2,846.				
	d Net gain or (loss)	••••••	-3,764.	-2,846.		-918.
ne	8 a Gross income from fundraising events (not including \$					
/en	of contributions reported on line 1c).					
Rei	See Part IV, line 18	116,738.				
er	<b>b</b> Less: direct expenses 8b	27,045.				
Other Revenue	c Net income or (loss) from fundraising event		89,693.			89,693.
•	9 a Gross income from gaming activities.		,			
	See Part IV, line 19					
	b Less: direct expenses 9b					
	c Net income or (loss) from gaming activities	►				
	10a Gross sales of inventory, less returns and allowances 10a					
	returns and allowances <b>10a</b> <b>b</b> Less: cost of goods sold <b>10b</b>					
	c Net income or (loss) from sales of inventory	v 🕨				
s		usiness Code				
Miscellaneous Revenue	11a					
scellaneo Revenue	b					
eve eve	c					
lisc R						
	e Total. Add lines 11a-11d					
	12 Total revenue. See instructions	▶	2,289,148.	-2,846.	0.	103,018.

## Form 990 (2019) CORNELIA DE LANGE SYNDROME FOUNDATION

#### 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 re	esponse or note to any	(B)	(C)		
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	<b>(D)</b> Fundraising expenses	
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21					
2 Grants and other assistance to domestic individuals. See Part IV, line 22	24,447.	24,447.			
3 Grants and other assistance to foreign organizations, foreign governments, and for- eign individuals. See Part IV, lines 15 and 16					
<ul> <li>4 Benefits paid to or for members</li> <li>5 Compensation of current officers, directors, trustees, and key employees</li> </ul>	104,726.	94,670.	4,235.	5,821.	
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0.	0.	0.	0.	
7 Other salaries and wages	477,848.	431,966.	19,323.	26,559.	
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)					
9 Other employee benefits	9,337.	8,440.	378.	519.	
10 Payroll taxes	48,372.	43,727.	1,956.	2,689.	
11 Fees for services (nonemployees):					
a Management					
<b>b</b> Legal					
<b>c</b> Accounting					
<b>d</b> Lobbying					
${\bf e}$ Professional fundraising services. See Part IV, line 17					
f Investment management fees					
<ul> <li>g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule 0.)</li> <li>12 Advertising and promotion</li> </ul>					
13 Office expenses	6,676.	29.	6,121.	526.	
14 Information technology				0200	
15 Royalties					
16 Occupancy	37,786.	34,386.	1,511.	1,889.	
17 Travel	- ,	- ,	,	,	
18 Payments of travel or entertainment expenses for any federal, state, or local public officials					
<b>19</b> Conferences, conventions, and meetings					
20 Interest					
21 Payments to affiliates					
<b>22</b> Depreciation, depletion, and amortization	6,158.		6,158.		
23 Insurance	6,712.	6,068.	271.	373.	
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)					
a PROFESSIONAL FEES	76,366.	41,745.	26,723.	7,898.	
<pre>b MEETING/SEMINARS</pre>	47,030.	21,754.	14,281.	10,995.	
• PRINTING_AND_PUBLICATIONS	25,505.	17,177.	1,029.	7,299.	
d EQUIPMENT_RENTAL	24,683.	21,687.	2,644.	352.	
e All other expenses	59,138.	30,827.	5,087.	23,224.	
25 Total functional expenses. Add lines 1 through 24e	954,784.	776,923.	89,717.	88,144.	
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► if following					
SOP 98-2 (ASC 958-720)				Earm <b>000</b> (2010)	

#### Form 990 (2019) CORNELIA DE LANGE SYNDROME FOUNDATION

Pa	rt X	Balance Sheet					
		Check if Schedule O contains a response or note to	o any line i	in this Part X			
					<b>(A)</b> Beginning of year		<b>(B)</b> End of year
	1	Cash – non-interest-bearing.			155,846.	1	308,499.
	2	Savings and temporary cash investments			62,421.	2	150,080.
	3	Pledges and grants receivable, net			100,000.	3	876,593.
	4	Accounts receivable, net				4	
	5	Loans and other receivables from any current or form trustee, key employee, creator or founder, substantial controlled entity or family member of any of these per	er officer, contributo rsons	director, or, or 35%		5	
	6	Loans and other receivables from other disqualified p					
		section 4958(f)(1)), and persons described in section	4958(c)(3)	(B)		6	
	7	Notes and loans receivable, net				7	
sts	8	Inventories for sale or use			3,659.	8	3,188.
Assets	9	Prepaid expenses and deferred charges			6,304.	9	26,614.
Ä	10 a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a	71,791.			
	b	Less: accumulated depreciation		41,237.	12,625.	10 c	30,554.
		Investments – publicly traded securities		,	657,547.	11	934,580.
	12	Investments – other securities. See Part IV, line 11			00770177	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	118,122.
	16	Total assets. Add lines 1 through 15 (must equal line			999,632.	16	2,448,230.
	17	Accounts payable and accrued expenses			16,711.	17	11,542.
	18	Grants payable				18	
	19	Deferred revenue			7,800.	19	6,235.
	20	Tax-exempt bond liabilities				20	
ies		Escrow or custodial account liability. Complete Part I				21	
Liabilities	22	Loans and other payables to any current or former off key employee, creator or founder, substantial contribu- controlled entity or family member of any of these per	utor. or 359	%		22	
	23	Secured mortgages and notes payable to unrelated th	nird parties			23	
	24	Unsecured notes and loans payable to unrelated third	parties	•		24	
	25	Other liabilities (including federal income tax, payable and other liabilities not included on lines 17-24). Com	es to relate plete Part	ed third parties, X of Schedule D.		25	
	26	Total liabilities. Add lines 17 through 25		•	24,511.	26	17,777.
S		Organizations that follow FASB ASC 958, check here	e► X				,
ő		and complete lines 27, 28, 32, and 33.		1			
alai	27	Net assets without donor restrictions			866,717.	27	1,397,281.
ã	28	Net assets with donor restrictions		· · · · · · <u>· · ·</u> · · · · · · · · · ·	108,404.	28	1,033,172.
Fund Balances		Organizations that do not follow FASB ASC 958, che and complete lines 29 through 33.	ck here ►				
5	29	Capital stock or trust principal, or current funds				29	
ets	30	Paid-in or capital surplus, or land, building, or equipm	nent fund	· · · · · · · · · · · · · · · · · · ·		30	
ŏ	31	Retained earnings, endowment, accumulated income,	or other f	unds		31	
- <b>v</b> .					075 101	22	0 400 450
Net Assets or	32	Total net assets or fund balances			975,121.	32	2,430,453.

Form 990 (2019)

Forr	1 990 (2019) CORNELIA DE LANGE SYNDROME FOUNDATION 0	6-105749	7	Pa	age <b>12</b>
Pa	t XI Reconciliation of Net Assets				
	Check if Schedule O contains a response or note to any line in this Part XI.				
1	Total revenue (must equal Part VIII, column (A), line 12)	1	2,2	89,1	L48.
2	Total expenses (must equal Part IX, column (A), line 25)			54,	
3	Revenue less expenses. Subtract line 2 from line 1	3	1,3	34,3	364.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4			121.
5	Net unrealized gains (losses) on investments	5			968.
6	Donated services and use of facilities	6			
7	Investment expenses	7			
8	Prior period adjustments	8			
9	Other changes in net assets or fund balances (explain on Schedule O)	9			0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32,				
	column (B))	10	2,4	30,4	<u>453.</u>
Pa	t XII Financial Statements and Reporting				
	Check if Schedule O contains a response or note to any line in this Part XII				. П
				Yes	No
1	Accounting method used to prepare the Form 990: Cash X Accrual Other				
	If the organization changed its method of accounting from a prior year or checked 'Other,' explain				
	in Schedule O.				
2:	a Were the organization's financial statements compiled or reviewed by an independent accountant?		2a		Х
	If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or revi	ewed on a			
	separate basis, consolidated basis, or both:				
	Separate basis Consolidated basis Both consolidated and separate basis				
I	Were the organization's financial statements audited by an independent accountant?		2 b	Х	
	If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a sep	oarate			
	basis, consolidated basis, or both:				
	X Separate basis Consolidated basis Both consolidated and separate basis				
(	If 'Yes' to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the at review, or compilation of its financial statements and selection of an independent accountant?	ıdit,	2 c	Х	
	If the organization changed either its oversight process or selection process during the tax year, explain				
	on Schedule O.				
3	a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Singl Audit Act and OMB Circular A-133?	e	. 3a		х
	<b>)</b> If 'Yes,' did the organization undergo the required audit or audits? If the organization did not undergo the required		50		
	or audits, explain why on Schedule O and describe any steps taken to undergo such audits		3b		
BAA				990	(2019)
			1 0111		()

SCHEDULE A	
(Form 990 or 990-EZ)	

# Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust. ► Attach to Form 990 or Form 990-EZ

OMB No. 1545-0047 2019

Departi Interna	ment of the Treasury I Revenue Service	F (	Go to www.irs.gov/Fo	orm990 for instructions	and the	latest i	nformation.	Inspection
	of the organization			_			Employer identifica	
			OME FOUNDATION			1 a 1 la i a	06-105749	
Par				rganizations must o For lines 1 through 12,				lions.
	<u> </u>	•		hurches described in sec		2	,	
1 2				Schedule E (Form 990 or			ı).	
2				ization described in sec			()/iii)	
4		•		unction with a hospital				nter the hospital's
-	name, city, a	-						
5	An organizati	ion operated for		ege or university owned		ated by	a governmental unit de	escribed in
6	A federal, sta	ate, or local gov	ernment or governme	ental unit described in s	ection 1	<b>70(b)(</b> 1)	)(A)(∨).	
7	An organization	on that normally (0(b)(1)(A)(vi).	receives a substantial p Complete Part II.)	part of its support from a	governm	ental un	it or from the general pul	blic described
8	A community	r trust described	l in section 170(b)(1)(	(A)(vi). (Complete Part I	II.)			
9	An agricultura	l research organ	ization described in sec	ction 170(b)(1)(A)(ix) oper	ated in c	onjunctio	on with a land-grant colle	ge
				e (see instructions). Enter				
10	from activitie	s related to its acome and unre	exempt functions—sul	a 33-1/3% of its support fr bject to certain exceptic e income (less section Part III.)	ons, and	(2) no	more than 33-1/3% of i	ts support from gross
11				ely to test for public safe	ety. See	section	n 509(a)(4).	
12	An organizati	ion organized a	nd operated exclusive	ely for the benefit of, to	perform	the fur	nctions of, or to carry or	It the purposes of one
	or more publi	icly supported of	organizations describe	ed in section 509(a)(1) of upporting organization	or <b>sectio</b>	n 509(a	)(2). See section 509(a	(3). Check the box in
а	Type I. A support	orting organizati	on operated, supervise gularly appoint or elec	d, or controlled by its sup t a majority of the directo	oported o	rganizat	ion(s), typically by giving	the supported on. <b>You must</b>
b	Type II. A sup	pporting organiz	zation supervised or o organization vested in	controlled in connection the same persons that c	with its ontrol or	support manage	ted organization(s), by the supported organizat	having control or ion(s). <b>You</b>
С	·			tion operated in connectio plete Part IV, Sections	n with, ar <b>A, D, an</b>	nd functi d E.	onally integrated with, its	supported
d	<b>Type III non-fu</b> functionally in	unctionally integ	rated. A supporting org	panization operated in cor must satisfy a distribu ms A and D, and Part V.	nnection	with its	supported organization(s)	that is not
е	Check this bo	ox if the organiz	ation received a writt	en determination from	the IRS	that it is	s a Type I, Type II, Type	e III functionally
,				supporting organization				
			n about the supported	d organization(s)				
	(i) Name of supported of	÷	(ii) EIN	(iii) Type of organization	(iv)	a tha	(v) Amount of monetary	(vi) Amount of other
		Sigunization		(described on lines 1-10 above (see instructions))		ion listed overning	support (see instructions)	support (see instructions)
					Yes	No		
(A)								
(B)								
(C)								
(D)								
(E)								
Total								

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

#### Section A. Public Support

Cale begi	ndar year (or fiscal year nning in) ►	<b>(a)</b> 2015	<b>(b)</b> 2016	<b>(c)</b> 2017	<b>(d)</b> 2018	<b>(e)</b> 2019	<b>(f)</b> 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						
Sec	tion B. Total Support						
Cale begi	ndar year (or fiscal year nning in) ►	<b>(a)</b> 2015	<b>(b)</b> 2016	<b>(c)</b> 2017	<b>(d)</b> 2018	<b>(e)</b> 2019	<b>(f)</b> Total
7	Amounts from line 4						
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
9	Net income from unrelated business activities, whether or not the business is regularly carried on						
10	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11	Total support. Add lines 7 through 10						
12	Gross receipts from related activ	vities, etc. (see in	structions)			12	
13	First five years. If the Form 990 is organization, check this box and						►
Sec	tion C. Computation of Pul	blic Support F	Percentage				
	Public support percentage for 20	-					%
	Public support percentage from		-				%
16a	<b>33-1/3% support test-2019.</b> If t and <b>stop here.</b> The organization	he organization d qualifies as a pu	id not check the b blicly supported c	oox on line 13, an organization	d line 14 is 33-1/3	3% or more, check	this box     ▶     □
b	33-1/3% support test-2018. If the and stop here. The organization	e organization di qualifies as a pu	d not check a box blicly supported o	on line 13 or 16a	a, and line 15 is 3	3-1/3% or more, c	heck this box
17a	<b>10%-facts-and-circumstances te</b> or more, and if the organization the organization meets the 'facts	meets the 'facts-	and-circumstance	s' test, check this	box and stop her	re. Explain in Part	VI how
	<b>10%-facts-and-circumstances te</b> or more, and if the organization organization meets the 'facts-an	meets the 'facts- d-circumstances'	and-circumstance test. The organiz	s' test, check this ation qualifies as	box and <b>stop he</b> a publicly support	re. Explain in Part ed organization.	: VI how the
18	Private foundation. If the organized	zation did not che	eck a box on line	13, 16a, 16b, 17a	, or 17b, check th	is box and see ins	structions ►
BAA					Sc	hedule A (Form 99	0 or 990-EZ) 2019

Schedule A (Form 990 or 990-EZ) 2019

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#### Schedule A (Form 990 or 990-EZ) 2019 CORNELIA DE LANGE SYNDROME FOUNDATION

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

#### Section A. Public Support (c) 2017 Calendar year (or fiscal year beginning in) > (a) 2015 (b) 2016 (d) 2018 (e) 2019 (f) Total Gifts, grants, contributions, 1 and membership fees received. (Do not include any 'unusual grants.')... 736,238 839,906 743,850 899,379. 1,843,159 5,062,532. 2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose... 108,734 101,365 89,693 98,174 85,818 483,784. 3 Gross receipts from activities that are not an unrelated trade or business under section 513. 0. Tax revenues levied for the organization's benefit and either paid to or expended on 0. its behalf.... The value of services or facilities furnished by a governmental unit to the organization without charge ... 0. Total. Add lines 1 through 5... 834,412 925,724 852,584 1 000,744 932 852 5, 546 316. Amounts included on lines 1, 7a 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.). 5,546,316. Section B. Total Support (c) 2017 (e) 2019 (a) 2015 (b) 2016 (d) 2018 Calendar year (or fiscal year beginning in) ► (f) Total 9 Amounts from line 6..... 834,412 925,724 852,584 1 000,744. 1. 932,852 5,546,316. 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from <u>6,</u>506 <u>7,</u>099 similar sources . 7,302 10,714 14,243 45,864. **b** Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975... c Add lines 10a and 10b ..... 7,302 6,506 7,099 10,714 14,243 45,864. 11 Net income from unrelated business activities not included in line 10b. whether or not the business is regularly carried on . . . . . . . 0. 12 Other income. Do not include gain or loss from the sale of capital assets (Explain in 0. Part VI.)... 13 Total support. (Add lines 9, 10c, 11, and 12)..... 933,026. 859,683. 840,918. 1,011,458. 5,592,180. 1,947,095 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) 14 ► organization, check this box and stop here. Section C. Computation of Public Support Percentage 15 Public support percentage for 2019 (line 8, column (f), divided by line 13, column (f))..... 15 % 99.18 16 Public support percentage from 2018 Schedule A, Part III, line 15. 16 Ŷ 98.35 Section D. Computation of Investment Income Percentage 17 Investment income percentage for 2019 (line 10c, column (f), divided by line 13, column (f))..... 17 0.82 0\0 18 Investment income percentage from 2018 Schedule A, Part III, line 17 ..... 0\0 18 1.65 19a 33-1/3% support tests-2019. If the organization did not check the box on line 14, and line 15 is more than 33-1/3%, and line 17 Х is not more than 33-1/3%, check this box and stop here. The organization gualifies as a publicly supported organization ... **b** 33-1/3% support tests - 2018. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33-1/3%, and line 18 is not more than 33-1/3%, check this box and stop here. The organization gualifies as a publicly supported organization. Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ..... 20

Part III

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#### Page 4

No

Yes

1

2

3a

3b

3c

4a

Δh

4c

5a

5b

5c

6

7

8

9a

9b

9c

10a

10b

#### Part IV Supporting Organizations

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

#### Section A. All Supporting Organizations

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

## Part IV Supporting Organizations (continued)

- 11 Has the organization accepted a gift or contribution from any of the following persons?a A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?
  - **b** A family member of a person described in (a) above?

c A 35% controlled entity of a person described in (a) or (b) above? If 'Yes' to a, b, or c, provide detail in Part VI.

#### Section B. Type I Supporting Organizations

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

#### Section C. Type II Supporting Organizations

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

#### Section D. All Type III Supporting Organizations

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

#### Section E. Type III Functionally Integrated Supporting Organizations

- 1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).
  - a The organization satisfied the Activities Test. Complete line 2 below.
  - **b** The organization is the parent of each of its supported organizations. *Complete line 3 below.*
  - c The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).

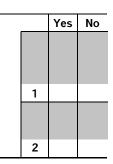
#### 2 Activities Test. Answer (a) and (b) below.

- a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If 'Yes,' then in **Part VI identify those supported** organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.
- **b** Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? *If 'Yes,' explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.*
- 3 Parent of Supported Organizations. Answer (a) and (b) below.
- a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? *Provide details in Part VI.*
- **b** Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If 'Yes,' describe in **Part VI** the role played by the organization in this regard.

		Yes	No					
	2a							
	2b							
	3a							
	3b							
2			2010					

11a

11b 11c



Yes

No

ection A – Adjusted Net Income		(A) Prior Year	(B) Current Year
•	-+		(optional)
1 Net short-term capital gain	1		
2 Recoveries of prior-year distributions	2		
3 Other gross income (see instructions)	3		
4 Add lines 1 through 3.	4		
5 Depreciation and depletion	5		
6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6		
7 Other expenses (see instructions)	7		
8 Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)	8		
ection B – Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):	t		
a Average monthly value of securities	1a		
<b>b</b> Average monthly cash balances	1b		
c Fair market value of other non-exempt-use assets	1c		
d Total (add lines 1a, 1b, and 1c)	1d		
e Discount claimed for blockage or other factors (explain in detail in Part VI):			
2 Acquisition indebtedness applicable to non-exempt-use assets	2		
3 Subtract line 2 from line 1d.	3		
<b>4</b> Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions).	4		
5 Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6 Multiply line 5 by .035.	6		
7 Recoveries of prior-year distributions	7		
8 Minimum Asset Amount (add line 7 to line 6)	8		
ection C – Distributable Amount			Current Year
1 Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2 Enter 85% of line 1.	2		
3 Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4 Enter greater of line 2 or line 3.	4		
-	5		

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

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Schedule A (Form 990 or 990-EZ) 2019

#### Schedule A (Form 990 or 990-EZ) 2019 CORNELIA DE LANGE SYNDROME FOUNDATION

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Par	t V   Type III Non-Functionally Integrated 509(a)(3) St	upporting Organiza	ations (continued)	
Sec	tion D – Distributions			Current Year
1	Amounts paid to supported organizations to accomplish exempt pu	irposes		
2	Amounts paid to perform activity that directly furthers exempt purposes in excess of income from activity	of supported organizatior	IS,	
3	Administrative expenses paid to accomplish exempt purposes of su	upported organizations		
4	Amounts paid to acquire exempt-use assets			
5	Qualified set-aside amounts (prior IRS approval required)			
6	Other distributions (describe in Part VI). See instructions.			
7	Total annual distributions. Add lines 1 through 6.			
8	Distributions to attentive supported organizations to which the organizati in <b>Part VI</b> ). See instructions.	ion is responsive (provide	e details	
9	Distributable amount for 2019 from Section C, line 6			
10	Line 8 amount divided by line 9 amount			
Sec	tion E – Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2019	(iii) Distributable Amount for 2019
1	Distributable amount for 2019 from Section C, line 6			
2	Underdistributions, if any, for years prior to 2019 (reasonable cause required – explain in Part VI). See instructions.			
3	Excess distributions carryover, if any, to 2019			
-	From 2014			
b	Prom 2015			
C	From 2016			
	From 2017			
e	PFrom 2018			
1	f Total of lines 3a through e			
g	Applied to underdistributions of prior years			
h	Applied to 2019 distributable amount			
i	i Carryover from 2014 not applied (see instructions)			
j	Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4	Distributions for 2019 from Section D, line 7: \$			
а	Applied to underdistributions of prior years			
b	Applied to 2019 distributable amount			
C	Remainder. Subtract lines 4a and 4b from 4.			
5	Remaining underdistributions for years prior to 2019, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.			
6	Remaining underdistributions for 2019. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7	Excess distributions carryover to 2020. Add lines 3j and 4c.			
8	Breakdown of line 7:			
а	Excess from 2015			
	Excess from 2016			
c	Excess from 2017			
d	Excess from 2018			
e	Excess from 2019			

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Schedule A (Form 990 or 990-EZ) 2019

Schedule B		OMB No. 1545-0047	
(Form 990, 990-EZ,	Schedule of Contributors	2010	
or 990-PF) Department of the Treasury Internal Revenue Service	<ul> <li>Attach to Form 990, Form 990-EZ, or Form 990-PF.</li> <li>Go to www.irs.gov/Form990 for the latest information.</li> </ul>	2019	
Name of the organization		Employer identification number	
CORNELIA DE LA	NGE SYNDROME FOUNDATION	06-1057497	
Organization type (che	eck one):		
Filers of:	Section:		
Form 990 or 990-EZ	X 501(c)( 3 ) (enter number) organization		
	4947(a)(1) nonexempt charitable trust <b>not</b> treated as a private foundation	on	
Form 990-PF	527 political organization		
	501(c)(3) exempt private foundation		
	4947(a)(1) nonexempt charitable trust treated as a private foundation		
	501(c)(3) taxable private foundation		

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

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

#### General Rule

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

#### Special Rules

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

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

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

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

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) (2019)	1	3	Page <b>2</b>
Name of organization	Employer identification number		
CORNELIA DE LANGE SYNDROME FOUNDATION	06-1057497		
Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.			

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	MARGARET WALTERS	-	Person X
	133 NORTH COLOGNE AVENUE	\$9,000.	Payroll Noncash
	EGG HARBOR CITY, NJ 08215		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2	WENDY AND ANDREW MILLER	_	Person X
	425 SEALE AVE	\$ <u>100,000.</u>	Payroll Noncash
	PALO ALTO, CA 94301		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
3	MS CATHERINE E CARON		Person X Payroll
	44_ROWELL_RD_E	\$ <u>5,000</u> .	Noncash
	BRENTWOOD, NH_03833	-	(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
(a) No. 	(b) Name, address, and ZIP + 4 MADISON COUNTY WOOD PRODUCTS INC	Total	Person X
	Name, address, and ZIP + 4	Total	
	Name, address, and ZIP + 4 MADISON COUNTY WOOD PRODUCTS INC	Total contributions	Person X Payroll
	Name, address, and ZIP + 4         MADISON COUNTY WOOD PRODUCTS INC         4597 HIGHWAY C	Total contributions	Person X Payroll Noncash (Complete Part II for
	Name, address, and ZIP + 4         MADISON COUNTY WOOD PRODUCTS INC         4597 HIGHWAY C         FREDERICKTOWN, MO_63645-7092         (b)	Total contributions	Person       X         Payroll       Image: Complete Part II for noncash contributions.)         (Complete Part II for noncash contributions.)         (d)         Type of contribution         Person       X
 (a) No.	Name, address, and ZIP + 4         MADISON_COUNTY_WOOD_PRODUCTS_INC         4597_HIGHWAY_C         FREDERICKTOWN, MO_63645-7092         (b)         Name, address, and ZIP + 4	Total contributions	Person X Payroll Noncash (Complete Part II for noncash contributions.) (d) Type of contribution
 (a) No.	Name, address, and ZIP + 4         MADISON COUNTY WOOD PRODUCTS INC         4597 HIGHWAY C         FREDERICKTOWN, MO_63645-7092         (b)         Name, address, and ZIP + 4         JOAN AND DAVID HANISCO         DO ROY 480	Total contributions       \$5,000.       (c)       Total contributions       \$5,000.	Person       X         Payroll       Image: Complete Part II for noncash contributions.)         (Complete Part II for noncash contributions.)         (d)         Type of contribution         Person       X         Payroll       Image: Contribution
 (a) No.	Name, address, and ZIP + 4         MADISON COUNTY WOOD PRODUCTS INC         4597 HIGHWAY C         FREDERICKTOWN, MO 63645-7092         Name, address, and ZIP + 4         JOAN AND DAVID HANISCO         PO BOX 480	Total contributions       \$5,000.       (c)       Total contributions       \$5,000.	Person       X         Payroll       Image: Complete Part II for noncash contributions.)         (Complete Part II for noncash contributions.)         (d)         Type of contribution         Person       X         Payroll       Image: Complete Part II for noncash         Noncash       Image: Complete Part II for noncash
4 (a) No.	Name, address, and ZIP + 4          MADISON COUNTY WOOD PRODUCTS INC         4597 HIGHWAY C         FREDERICKTOWN, MO 63645-7092         (b)         Name, address, and ZIP + 4         JOAN AND DAVID HANISCO         PO BOX 480         RUSHLAND, PA 18956-0480	Total contributions	Person       X         Payroll       X         Noncash       X         (Complete Part II for noncash contributions.)       X         Type of contribution       X         Person       X         Payroll       X         Noncash       X         Yupe of contributions.)       X         Person       X         Type of contributions.)       X         Payroll       X         Noncash       X         Yupe of contributions.)       X         Person       X
4 (a) No. 5	Name, address, and ZIP + 4         MADISON_COUNTY_WOOD_PRODUCTS_INC         4597_HIGHWAY_C         FREDERICKTOWN, MO_63645-7092         FREDERICKTOWN, MO_63645-7092         Name, address, and ZIP + 4         JOAN_AND_DAVID_HANISCO         PO_BOX_480         RUSHLAND, PA_18956-0480         Name, address, and ZIP + 4	Total contributions	Person       X         Payroll

Schedule B (Form 990, 990-EZ, or 990-PF) (2019)	2	3	Page 2
Name of organization	Employer identification number	r	
CORNELIA DE LANGE SYNDROME FOUNDATION	06-1057497		
Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.			

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	JULIE AND FRANK MAIRANO	-	Person X Payroll
	85 EAST INDIA ROW 39F	\$ <u>10,000.</u>	Noncash
	BOSTON, MA_02110		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
8	WILLIAM AND ALICE MORTENSEN FOUNDAT	-	Person X
	PO_BOX_230212	\$6,235.	Payroll Noncash
	HARTFORD, CT_06123		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
9	MARY ANN AND PAT FEEHAN	_	Person X
	584 NORTHLAWN DR	\$ <u>5,108.</u>	Payroll Noncash
	LANCASTER, PA_17603-2381	-	(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
(a) No.		(c) Total contributions	Type of contribution Person
	Name, address, and ZIP + 4	(c) Total contributions \$10,500.	Type of contribution
	Name, address, and ZIP + 4 SUSAN AND DAVID FOWLER	contributions	Type of contribution       Person     X       Payroll
	Name, address, and ZIP + 4         SUSAN_AND_DAVID_FOWLER	contributions	Type of contribution         Person       X         Payroll
<u>10</u> _ (a)	Name, address, and ZIP + 4         SUSAN_AND_DAVID_FOWLER	contributions	Type of contribution         Person       X         Payroll       Image: Complete Part II for noncash contributions.)         (Complete Part II for noncash contributions.)         (d)         Type of contribution         Person       X
<u>10</u>	Name, address, and ZIP + 4         SUSAN_AND_DAVID_FOWLER         10_WILLIAM_ST         RUMSON, NJ_07760         (b)         Name, address, and ZIP + 4	contributions	Type of contribution         Person       X         Payroll          Noncash          (Complete Part II for noncash contributions.)          (d)          Type of contribution
<u>10</u>	Name, address, and ZIP + 4         SUSAN AND DAVID FOWLER         10_WILLIAM_ST         RUMSON, NJ_07760         (b)         Name, address, and ZIP + 4         RUTH_B_WILSON	contributions	Type of contribution         Person       X         Payroll       Image: Complete Part II for noncash contributions.)         (Complete Part II for noncash contributions.)       (d)         Type of contribution       X         Person       X         Payroll       Image: Contribution
<u>10</u>	Name, address, and ZIP + 4         SUSAN_AND_DAVID_FOWLER	contributions	Type of contribution         Person       X         Payroll       Image: Complete Part II for noncash contributions.)         (Complete Part II for noncash contributions.)         (d)         Type of contribution         Person       X         Payroll       Image: Complete Part II for noncash         (Complete Part II for noncash       Image: Complete Part II for noncash         Person       X         Payroll       Image: Complete Part II for noncash
<u>10</u> _ (a) No. <u>11</u> _	Name, address, and ZIP + 4         SUSAN AND DAVID FOWLER         10 WILLIAM ST         RUMSON, NJ 07760         (b)         Name, address, and ZIP + 4         RUTH B WILSON         865 CENTRAL AVE., APT M205         NEEDHAM, MA 02492         (b)	contributions	Type of contribution         Person       X         Payroll       Image: Complete Part II for noncash contributions.)         Complete Part II for noncash contribution       X         Person       X         Payroll       Image: Complete Part II for noncash contributions.)         Visit Payroll       Image: Complete Part II for noncash contributions.)         Complete Part II for noncash contributions.)       Complete Part II for noncash contributions.)         Complete Part II for noncash contributions.)       X         Person       X         Person       X
<u>10</u>	Name, address, and ZIP + 4         SUSAN_AND_DAVID_FOWLER	contributions	Type of contribution         Person       X         Payroll       Image: Complete Part II for noncash contributions.)         (Complete Part II for noncash contribution       X         Person       X         Payroll       Image: Complete Part II for noncash         Noncash       Image: Complete Part II for noncash contributions.)         Ype of contributions.)       X         Payroll       Image: Complete Part II for noncash contributions.)         (Complete Part II for noncash contributions.)       (Complete Part II for noncash contributions.)         (D)       Type of contribution

Schedule B (Form 990, 990-EZ, or 990-PF) (2019)	3	3	Page <b>2</b>
Name of organization	Employer identification number	r	
CORNELIA DE LANGE SYNDROME FOUNDATION	06-1057497		
Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.			

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>13</u>	GAYLE AND STEVE MCCUE 5351 WILLOWICK DR ANAHEIM, CA 92807	\$428,534.	Person     X       Payroll        Noncash        (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>14</u> _	PALLET_LOGISTICS_MANAGEMENT, INC 3311_CHOUTEAU_AVE SAINT_LOUIS, MO_63103	\$ <u>5,000</u> .	Person     X       Payroll     Image: Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>15</u>	LYNNE KERR AND HUNTER JACKSON         142 N YOUNG OAK RD         SALT LAKE CITY, UT 84108	\$6,200.	Person     X       Payroll     Image: Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>16</u> _	DIVA DANCE_COMPETITION, INC 2_IVY_COURT NORFOLK, MA_02056	\$ <u>5,000</u> .	Person     X       Payroll     Image: Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>17</u>	DOZMATI TRUST 4707 EXECUTIVE BLVD SAN DIEGO, CA 92121	\$20,000.	Person     X       Payroll        Noncash        (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
	 	\$	Person

Schedule B (Form 990, 990-EZ, or 990-PF) (2019)		1	Page <b>3</b>
Name of organization	Employer identif	ication num	lber
CORNELIA DE LANGE SYNDROME FOUNDATION	06-10574	97	

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

artii	<b>Noncash Property</b> (see instructions). Use duplicate copies of Part II if additional space is needed.				
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
	N/A				
		 \$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		\$			
(a) No	(b)	(c)	(4)		
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		s			
		'			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		\$			
(a) N-		(-)	(_\\		
a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
	L				
		]\$			
A		Schedule B (Form 990, 990-E			

	3 (Form 990, 990-EZ, or 990-PF) (2019)			1 1 Page <b>4</b>
Name of organ	nization LA DE LANGE SYNDROME FOUNDAT	TON		Employer identification number $06-1057497$
	<i>Exclusively</i> religious, charitable, et or (10) that total more than \$1,000 for t the following line entry. For organizations of contributions of \$1,000 or less for the year. Use duplicate copies of Part III if additional	tc., contributions to organ he year from any one contrib ompleting Part III, enter the tota (Enter this information once. Se	utor. Comple	<b>described in section 501(c)(7), (8),</b> te columns (a) through (e) and e/v religious, charitable, etc.,
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held
	N/A			
				<u> </u>
	Transferee's name, addres	(e) Transfer of gift s, and ZIP + 4	Rela	itionship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held
				·
	Transferee's name, addres	(e) Transfer of gift s, and ZIP + 4	Rela	tionship of transferor to transferee
(a) No. from	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held
Part I		<b>_</b>		
				·
	(e) Transfer of gift Transferee's name, address, and ZIP + 4		Rela	tionship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held
	L			└
	Transferee's name, addres	(e) Transfer of gift s, and ZIP + 4	Rela	tionship of transferor to transferee
BAA			Sche	

SCI	HEDULE D	Sup	plemental Financial S	tatements			OMB No	. 1545-0047	
	rm 990)	► Complet	te if the organization answered ' 5, 7, 8, 9, 10, 11a, 11b, 11c, 11d, '	2019					
Depar Intern	tment of the Treasury al Revenue Service		Attach to Form 990.	<ul> <li>Attach to Form 990.</li> <li>gov/Form990 for instructions and the latest information.</li> </ul>					
Name	of the organization					Employer id	Inspect Inspection I		
		DE LANGE SYNDROME				06-105	7497		
Par	t I Organizat	tions Maintaining Dong	or Advised Funds or Other wered 'Yes' on Form 990,	r <b>Similar Funds</b> Part IV line 6	s or Acc	counts.			
	Complete		(a) Donor advised fu		(h) E	unds and	othor acco	unto	
1	Total number at e	end of year		nus	(D) F	unus anu i		ounts	
2		ntributions to (during year).							
2		ants from (during year)							
4		at end of year							
5		-	L nor advisors in writing that the a	ccotc hold in dono	, advicad	funde			
-	are the organizat	ion's property, subject to the	organization's exclusive legal co	ontrol?		· · · · · · · L	Yes	No	
6	for charitable pur	poses and not for the benefit	ors, and donor advisors in writing t of the donor or donor advisor, o	or for any other pu	rpose cor	nferring _	7.2	<b>—</b>	
							Yes	No	
Par		tion Easements.	wared Weel on Form 000	Dort IV/ line 7					
1			wered 'Yes' on Form 990, y the organization (check all that						
1				Preservation	of a histo	rically imp	ortant lan	daraa	
		of land for public use (for exam natural habitat	pie, recreation of education)			, ,			
				Preservation	or a certi	neu mistori	c structure	;	
2		of open space							
2	last day of the ta		held a qualified conservation contri	bution in the form of					
						leld at the	End of th	e Tax Year	
			· · · · · · · · · · · · · · · · · · ·		2 a				
			ments	-	2 b				
			fied historic structure included in		2 c				
C	Number of conse structure listed in	rvation easements included in the National Register	n (c) acquired after 7/25/06, and	I not on a historic	2 d				
3	Number of conserv tax year ►	vation easements modified, tran	nsferred, released, extinguished, or	terminated by the c	organizatio	on during th	e		
4	Number of states v	where property subject to conse	ervation easement is located ►						
5	Does the organization	ation have a written policy re	egarding the periodic monitoring,	inspection, handlin	ng of viol	ations,	7.7	<b>—</b>	
6			nts it holds? inspecting, handling of violations, a					<b>No</b>	
Ŭ		r nouro dovotod to monitoring,			valion ou				
7	Amount of expense ►\$	es incurred in monitoring, inspe	ecting, handling of violations, and e	enforcing conservation	on easeme	ents during	the year		
8	Does each conse	rvation easement reported or	n line 2(d) above satisfy the requ	uirements of sectio	n 170(h)(	(4)(B)(i)	-	_	
0	and section 170(h	h)(4)(B)(ii)?					Yes	No	
9	include, if application conservation eas	able, the text of the footnote ements.	ports conservation easements in to the organization's financial sta	atements that desc	ribes the	organizati	on's accoi	unting for	
Par	t III Organizat Complete	tions Maintaining Colle if the organization ans	ections of Art, Historical Tr wered 'Yes' on Form 990,	<b>reasures, or Ot</b> Part IV, line 8.	her Sin	nilar Ass	ets.		
1a	historical treasure	es, or other similar assets he	r FASB ASC 958, not to report in Id for public exhibition, education al statements that describes thes	n, or research in fu	ment and urtherance	l balance s e of public	heet work service, p	s of art, provide in	
ł	historical treasures following amount	s, or other similar assets held f s relating to these items:	r FASB ASC 958, to report in its or public exhibition, education, or re	esearch in furtheran	ce of publ	ic service,	t works of provide the	art,	
	••		line 1			_			
	· · /	-							
	amounts required	to be reported under FASB	nistorical treasures, or other similar ASC 958 relating to these items	:			lowing		
			. 1						
ваа	For Paperwork R	reduction Act Notice, see the	e Instructions for Form 990.	IEEA3301L 8/2	2/19	Sched	uie D (F0)	m 990) 2019	

BAA For Paper	work Reduction	Act Notice, see	the Instructions	for Form 99
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Schedule D (Form 990) 2019 CORN							06-105			Page 2
Part III Organizations Mainta	ining Colle	ections	of Art, Histo	orical	Treasures, or	r Other Si	milar Asse	ets (co	ontinu	ed)
<b>3</b> Using the organization's acquisition items (check all that apply):	n, accession, a	and other	records, check a	any of t	he following that m	nake significa	nt use of its o	collectio	n	
<b>a</b> Public exhibition			<b>d</b> Loan	or exc	hange program					
<b>b</b> Scholarly research			e Other		nange program					
<b>c</b> Preservation for future gene	rations									
<ul> <li>Provide a description of the organi.</li> <li>Part XIII.</li> </ul>	zation's collect	ions and	explain how the	y furthe	er the organization'	s exempt pu	rpose in			
5 During the year, did the organizato be sold to raise funds rather t	ation solicit or han to be ma	receive	donations of an	rt, histo proaniz	orical treasures, c ation's collection	or other simi	lar assets	Yes	Г	No
Part IV Escrow and Custodia	al Arrangen	nents. (	Complete if	the or	rganization an			rm 990	), Par	
line 9, or reported an	amount on	Form	990, Part X,	line 2	21.					
1 a Is the organization an agent, tru	stee, custodia	an or othe	er intermediary	for co	ntributions or oth	er assets no	t included			
on Form 990, Part X? <b>b</b> If 'Yes,' explain the arrangemen							· · · · · · · · · · L	Yes	L	No
<b>b</b> if fes, explain the arrangement	l III Parl AIII a	anu com		ing tat	ne.			Amount		
<b>c</b> Beginning balance						1c		Amount		
<b>d</b> Additions during the year										
e Distributions during the year										
f Ending balance										
2 a Did the organization include an							bility?	Yes		No
<b>b</b> If 'Yes,' explain the arrangemen							-			
									L	
Part V Endowment Funds.	Complete if	the org	anization ar	nswer	ed 'Yes' on Fo	orm 990, F	Part IV, lin	ne 10.		
	(a) Current	t year	(b) Prior yea	ar	(c) Two years back	< (d) Thr	ee years back	(e) F	our years	s back
<b>1 a</b> Beginning of year balance										
<b>b</b> Contributions										
c Net investment earnings, gains, and losses										
<b>d</b> Grants or scholarships										
e Other expenditures for facilities and programs										
f Administrative expenses										
<b>g</b> End of year balance										
2 Provide the estimated percentage	je of the curre	ent year e	end balance (lir	ne 1g,	column (a)) held	as:				
<b>a</b> Board designated or quasi-endown	nent 🕨 🔜		00							
b Permanent endowment ►	%	5								
c Term endowment	0/0									
The percentages on lines 2a, 2b, a	and 2c should e	equal 100	%.							
3 a Are there endowment funds not in	the possessior	n of the or	ganization that	are hel	d and administered	d for the		Г	Vee	N.
organization by: (i) Unrelated organizations								20(1)	Yes	No
(i) Related organizations								3a(i) 3a(ii)		<u> </u>
<b>b</b> If 'Yes' on line 3a(ii), are the rel								3b		
4 Describe in Part XIII the intende	-							50		L
Part VI Land, Buildings, and		-			1431					
Complete if the organ			'Yes' on For	m 99	0 Part IV line	11a See	• Form 99(	) Parl	tX lir	ne 10
Description of property			or other basis		Cost or other	(c) Accu			Book va	
			vestment)	(D)	basis (other)	deprec	ciation	(u) L	JUUK VA	liue
<b>1 a</b> Land										
<b>b</b> Buildings										
c Leasehold improvements										
<b>d</b> Equipment										
e Other					71,791.	4	41,237.			,554.
Total. Add lines 1a through 1e. (Colur	nn (d) must e	qual Forr	m 990, Part X,	colum	n (B), line 10c.)					,554.
BAA							Schedu	ule D (Fo	orm 990	) 2019

TEEA3302L 8/22/19

Schedule D (Form 990) 2019 CORNELIA DE LANGE	SYNDROME FOUND	ATION	06-1057497	Page 3
Part VII Investments – Other Securities.		N/A		
Complete if the organization answered				
(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuati	on: Cost or end-of-year market v	alue
<ol> <li>(1) Financial derivatives</li></ol>				
(2) 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. Complete if the organization answered	'Vac' on Form 000	N/A	Can Form 000 Dart V	/ lina 12
(a) Description of investment	(b) Book value	, Part IV, III e TTC. 3	: Cost or end-of-year mar	<u>, III e 13</u> ket value
			. Cost of end-of-year mar	Ket 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. Complete if the organization answered	N/A 'Yes' on Form 990	Part IV line 11d S	See Form 990 Part X	( line 15
· · · · · ·	scription		(b) Book	
(1)	·			
(2)				
(3)				
(4)				
(5) (6)				
(7) (8)				
(9)				
(10)				
Total. (Column (b) must equal Form 990, Part X, column (b)	B) line 15.)		▶	
Part X Other Liabilities.	arm 000 Dart IV line 11	a ar 11f Can Farm 000 F	Dart V Lina DE	
Complete if the organization answered 'Yes' on F 1. (a) Descr	iption of liability	e of 111. See Form 990, P	(b) Book	
(1) Federal income taxes				value
(2)				
(3)				
(4)				
(5)				
(6)				
(7)				
(8) (9)				
(10)				
(11)				
Total. (Column (b) must equal Form 990, Part X, column (B) line 25.)			►	
2. Liability for uncertain tax positions. In Part XIII, provide the text of the for	otnote to the organization's fir	nancial statements that reports t	he organization's liability for unc	
tax positions under FASB ASC 740. Check here if the text of the footnote has	been provided in Part XIII			🔲

Schedule D (Form 990) 2019 CORNELIA DE LANGE SYNDROME FOUNDATION (	06-1057497	Page 4
Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per I	Return.	
Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.		
1 Total revenue, gains, and other support per audited financial statements	. 1	2,437,159.
2 Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a Net unrealized gains (losses) on investments	3.	
b Donated services and use of facilities 2b		
c Recoveries of prior year grants 2c		
d Other (Describe in Part XIII.) SEE PART XIII 2d 27,043	· .	
e Add lines <b>2a</b> through <b>2d</b>	. 2e	148,011.
3 Subtract line 2e from line 1.	. 3	2,289,148.
4 Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a Investment expenses not included on Form 990, Part VIII, line 7b 4a		
b Other (Describe in Part XIII.)		
c Add lines <b>4a</b> and <b>4b</b>	. 4c	
5 Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	. 5	2,289,148.
Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per	r Return.	
Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.		
1 Total expenses and losses per audited financial statements	. 1	981,827.
2 Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a Donated services and use of facilities 2a		
b Prior year adjustments		
c Other losses		
d Other (Describe in Part XIII.) SEE PART XIII 2d 27,043		
e Add lines 2a through 2d		27,043.
3 Subtract line 2e from line 1		954,784.
4 Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a Investment expenses not included on Form 990, Part VIII, line 7b 4a		
b Other (Describe in Part XIII.)		
c Add lines 4a and 4b		
5 Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	. 5	954,784.
Part XIII Supplemental Information.		

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

# SCHEDULE D, PART XI, LINE 2D OTHER REVENUE INCLUDED IN F/S BUT NOT INCLUDED ON FORM 990

DIRECT EVENTS EXPENSES. TOTAL	\$ \$	-2. 27,045. 27,043.
SCHEDULE D, PART XII, LINE 2D OTHER EXPENSES AND LOSSES PER AUDITED F/S		
DIRECT EVENTS EXPENSES TOTAL	\$ \$	-2. 27,045. 27,043.

BAA

SCHEDULE G			• •	Fundraising or Gami orm 990, Part IV, line 17, 18	•	OMB No. 1545-0047
(Form 990 or 990-EZ)	orga	2019				
Department of the Treasury Internal Revenue Service	► Go to www			or Form 990-EZ. ructions and the latest	information.	Open to Public Inspection
Name of the organization					Employer identific	
CORNELIA DE LANGE S	. Complete if the o	rganization ans	wered 'Yes'	on Form 990, Part IV, line	06-105749 e 17.	<i>)</i> /
Part I Form 990-EZ filers a 1 Indicate whether the orga	ire not required to	complete this	part.			
a X Mail solicitations		nus through an	5	X Solicitation of non-	11.5	
<b>b</b> X Internet and email so	licitations		f	Solicitation of gove	ernment grants	
c Phone solicitations			g	X Special fundraising	g events	
<b>d</b> X In-person solicitations <b>2 a</b> Did the organization have a		eement with any	, individual (	including officers directo	ars trustees or key	
employees listed in Form <b>b</b> If 'Yes.' list the 10 highes	990, Part VII) or topaid individuals	entity in conne or entities (fun	ction with p	professional fundraising	services?	
compensated at least \$5,	UUU by the organi	zation.			(v) Amount paid to	
(i) Name and address of indi or entity (fundraiser)	vidual (ii) Act	have cust	d fundraiser tody or control itributions?	(iv) Gross receipts from activity	(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						
	I					
Total						0.
<b>3</b> List all states in which the or licensing.	organization is regis	stered or license	a to solicit d	contributions or has been	notified it is exempt from	n registration

Schedule G (Form 990 or 990-EZ) 2019	CORNELIA DE	E LANGE	SYNDROME	FOUNDATION
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06-1057497 Page 2

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

		Else events man gress receipts gre				
			(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
			• •		NONE	(add column <b>(a)</b>
Р			GOLF EVENTS-MO (event type)	GOLF EVENTS-NE	(total number)	through column (c)
Ē			(event type)	(event type)	(total number)	
REVENUE						
Ň	1	Gross receipts	74,895.	41,843.		116,738.
Ĕ						
	2	Less: Contributions.				
	3	Gross income (line 1 minus line 2)	74,895.	41,843.		116,738.
	_					
	4	Cash prizes				
_	5	Noncash prizes				
D	_					
	6	Rent/facility costs				
R E C T	_					
т	7	Food and beverages				
Ë						
Ê	8	Entertainment				
EXPENSE						
S	9	Other direct expenses	15,740.	11,305.		27,045.
E S						
-	10	Direct expense summary. Add lines 4 thr	ough 9 in column (d)		▶	27,045.
		Net income summary. Subtract line 10 fr				
	11					89,693.
Par	t III	Gaming. Complete if the organiza	ition answered 'Yes	s' on Form 990, Par	rt IV, line 19, or rej	ported more than
		\$15,000 on Form 990-EZ, line 6a.				
				(b) Dull tobe/instant		(d) Total coming
R			(a) Bingo	(b) Pull tabs/instant bingo/progressive	(c) Other gaming	(d) Total gaming (add column (a)
E V				bingo		through column (c)
R E V E N U E				5		3 (7
Ü						
Е	1	Gross revenue				
	_	Cook prizza				
_	2	Cash prizes.				
EXPENSES						
	3	Noncash prizes				
ËŇ						
TE		Rent/facility costs				
s	4					
	5	Other direct expenses				
			Yes %	Yes %	Yes %	
	6	Volunteer labor	No	No	No	
	Ŭ					
		<b>_</b>				
	7	Direct expense summary. Add lines 2 thr	ough 5 in column (d)		•••••	
	8	Net gaming income summary. Subtract li	ne 7 from line 1. colum	n (d)	►	
	_ <b>-</b>			、/ ·····		
9		er the state(s) in which the organization co				
ä	<b>a</b> Is th	ne organization licensed to conduct gaming	g activities in each of th	nese states?		Yes No
ł	n, lf 'N	lo,' explain:				
•						
10 a	a Wer	e any of the organization's gaming license	es revoked, suspended,	or terminated during th	e tax year?	Yes No
		(a. L. availation)				
•		· · · · · ·				

Schedule G (Form 990 or 990-EZ) 2019

Schedule G (Form 990 or 990-EZ) 2019 CORNELIA DE LANGE SYNDROME FOUNDATION	06-1057497	Page 3
11 Does the organization conduct gaming activities with nonmembers?	Yes	No
12 Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed to administer charitable gaming?		No
13 Indicate the percentage of gaming activity conducted in:	1 1	
<b>a</b> The organization's facility.		00
<b>b</b> An outside facility.		90
14 Enter the name and address of the person who prepares the organization's gaming/special events books and record	ds:	
Name ►		
Address ►		
<ul> <li>15a Does the organization have a contract with a third party from whom the organization receives gaming reverse b If 'Yes,' enter the amount of gaming revenue received by the organization ► \$ and of gaming revenue retained by the third party ► \$ c If 'Yes,' enter name and address of the third party:</li> </ul>	nue? <b>Yes</b> the amount	s 🗌 No
Name ►		1
Address ►		   
16 Gaming manager information:		
Name ►		
Gaming manager compensation <b>&gt;</b> \$		
Description of services provided		
Director/officer Employee Independent contractor		
17 Mandatory distributions:		
<b>a</b> Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?	Yes	5 🗌 No
<b>b</b> Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent i	n the	
organization's own exempt activities during the tax year ► \$		( )
<b>Part IV</b> Supplemental Information. Provide the explanations required by Part I, line 2b, c and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide a information. See instructions.	ny additional	(v);

SCHEDULE I	Grants and Other Assistance to Organizations,							OMB No. 1545-0047	
(Form 990)	Governments, and Individuals in the United States Complete if the organization answered 'Yes' on Form 990, Part IV, line 21 or 22.								
Department of the Treasury Internal Revenue Service		<ul> <li>Attach to Form 990.</li> <li>Go to www.irs.gov/Form990 for the latest information.</li> </ul>							
Name of the organization							Employer identific		
CORNELIA DE LAN							06-105749	7	
		rants and Assist		assistance, the grantees	l aligibility for the grapte	or accistance, and			
								X Yes No	
				nds in the United States.			ART IV		
Part II Grants and Form 990, I				and Domestic Gove nore than \$5,000. F					
<b>1 (a)</b> Name and addres or govern	ss of organization Iment	<b>(b)</b> EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance	
(1)									
(2)									
<u>(2)</u>									
(3)									
(4)									
<u></u>									
(5)									
(6)									
(7)									
(8)									
				in the line 1 table				0	
BAA For Paperwork Re					TEEA3901L		••••••••••••••••••••••••••••••••••••••	0 e I (Form 990) (2019)	

#### Schedule | (Form 990) (2019) CORNELIA DE LANGE SYNDROME FOUNDATION

06-1057497

Page 2

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered 'Yes' on Form 990, Part IV, line 22. Part III can be duplicated if additional space is needed.

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

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

#### PART I, LINE 2 - PROCEDURES FOR MONITORING USE OF GRANTS FUNDS IN U.S.

THE RESEARCH COMMITTEE REQUIRES A REPORT ON THE ONE-YEAR ANNIVERSARY OF THE GRANT

AWARD. THE REPORT MUST INCLUDE BUDGET ALLOCATION TO DATE, A SUMMARY OF RESEARCH

FINDINGS AND INFORMATION ON ANY PROFESSIONAL PAPERS PUBLISHED OR MANUSCRIPTS IN

SUBMISSION.

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

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

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

Name of the organization		Employer identification number
CORNELIA DE LANGE SYNDRO	E FOUNDATION	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 17 - LIST OF STATES WHICH THIS RETURN IS FILED

AZ CA CO CT FL GA IL KS KY LA ME MA MD MI MN MS MO NH NJ NM NY NC ND OH AL AK 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, THE FOUNDATION'S WEBSITE CDLSUSA.ORG AND THE ANNUAL REPORT.