

Cornelia de Lange
Syndrome Foundation, Inc.

FINANCIAL STATEMENTS

For the years ended
December 31, 2018 and 2017

Cornelia de Lange Syndrome Foundation, Inc.
Financial Statements
For the years ended December 31, 2018 and 2017

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To the Board of Directors of
Cornelia de Lange Syndrome Foundation, Inc.

Independent Auditor's Report

We have audited the accompanying financial statements of Cornelia de Lange Syndrome Foundation, Inc. (a nonprofit organization), which comprise the statements of financial position as of December 31, 2018 and 2017, and the related statements of activities, functional expenses, and cash flows for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Cornelia de Lange Syndrome Foundation, Inc. as of December 31, 2018 and 2017, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

Emphasis of Matters

As discussed in Note 1, Cornelia de Lange Syndrome Foundation, Inc. adopted Accounting Standards Update (ASU) No. 2016-14, Not-for-Profit Entities (Topic 958): Presentation of Financial Statements of Not-for-Profit Entities. Our opinion is not modified with respect to these matters.



Bottaro, Morrill & Company, LLC

July 30, 2019

Cornelia de Lange Syndrome Foundation, Inc.

Statements of Financial Position

December 31, 2018 and 2017

	2018	2017
Assets		
Current assets:		
Cash and cash equivalents	\$ 218,267	\$ 345,591
Investments	657,547	812,399
Promises to give	100,000	37,621
Prepaid expenses	6,304	11,607
Fundraising inventory	3,659	4,838
Total current assets	<u>985,777</u>	<u>1,212,056</u>
Fixed assets:		
Equipment	76,240	77,761
Less: accumulated depreciation	<u>(63,615)</u>	<u>(65,339)</u>
Total fixed assets, net	<u>12,625</u>	<u>12,422</u>
Other asset:		
Security deposit	<u>1,230</u>	<u>1,230</u>
Total assets	<u>\$ 999,632</u>	<u>\$ 1,225,708</u>
Liabilities and Net Assets		
Current liabilities:		
Accounts payable and accrued expenses	\$ 16,711	\$ 22,526
Deferred revenue	<u>7,800</u>	<u>-</u>
Total current liabilities	<u>24,511</u>	<u>22,526</u>
Net assets:		
Without donor restrictions:		
Undesignated funds	196,933	244,932
Board designated operating reserve	<u>669,784</u>	<u>820,951</u>
Total funds without donor restrictions	<u>866,717</u>	<u>1,065,883</u>
Net assets with donor restrictions	<u>108,404</u>	<u>137,299</u>
Total net assets	<u>975,121</u>	<u>1,203,182</u>
Total liabilities and net assets	<u>\$ 999,632</u>	<u>\$ 1,225,708</u>

See independent auditor's report and notes to financial statements

Cornelia de Lange Syndrome Foundation, Inc.
Statements of Activities
For the years ended December 31, 2018 and 2017

	2018	2017
Changes in net assets without donor restrictions:		
Support and revenues		
Contributions and donations	\$ 316,533	\$ 345,722
Special events	438,077	459,538
Grants	40,645	51,066
Fundraising merchandise sales, net of costs	(4,288)	(6,676)
National conference	132,509	-
Interest and dividend income, net of fees	10,714	7,099
Net realized and unrealized gains (losses)	(51,774)	90,736
Net assets released from restrictions	136,093	-
Total support and revenues	<u>1,018,509</u>	<u>947,485</u>
Expenses:		
Program Services		
Family support	517,390	311,260
Public information and education	216,562	210,464
Professional development, outreach and awareness	225,550	209,286
Research	34,420	56,314
Total program services	<u>993,922</u>	<u>787,324</u>
Management and general	98,485	79,362
Fundraising costs	70,811	69,685
Special events costs	54,457	61,343
Total expenses	<u>1,217,675</u>	<u>997,714</u>
Changes in net assets without donor restrictions	<u>(199,166)</u>	<u>(50,229)</u>
Changes in net assets with donor restrictions:		
Contributions and grants	107,198	46,543
Net assets released from restrictions	(136,093)	-
Changes in net assets with donor restrictions	<u>(28,895)</u>	<u>46,543</u>
Total change in net assets	\$ (228,061)	\$ (3,686)
Net assets, beginning of year	1,203,182	1,206,868
Net assets, end of year	<u>\$ 975,121</u>	<u>\$ 1,203,182</u>

See independent auditor's report and notes to financial statements

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.
Statements of Functional Expenses
For the years ended December 31, 2018 and 2017

Program Services

	Family Support Program		Public Information and Education		Professional Development, Outreach and Awareness		Research		Comparative Totals	
	2018	2017	2018	2017	2018	2017	2018	2017	2018	2017
Salaries, Payroll Taxes	\$ 238,410	\$ 222,610	\$ 147,438	\$ 135,879	\$ 175,670	\$ 161,898	\$ 6,274	\$ 5,782	\$ 567,792	\$ 526,169
Employee Benefits	-	-	-	-	-	-	-	-	-	-
Depreciation	-	-	-	-	-	-	-	-	-	-
Insurance	1,903	1,880	1,222	1,207	1,370	1,353	-	-	4,495	4,440
Meetings and Seminars	229,175	20,464	908	6,159	18,052	7,782	-	1,055	248,135	35,460
Office Expense	27	264	217	52	-	115	-	-	244	431
Postage	1,619	3,841	9,655	10,362	10	1,718	-	7	11,284	15,928
Professional Fees	14,045	32,879	24,060	21,818	14,720	20,752	-	-	52,825	75,449
Rent	15,289	15,289	8,494	8,494	6,795	6,795	340	340	30,918	30,918
Printing	1,943	1,584	14,707	18,484	584	883	-	-	17,234	20,951
Telephone	2,376	2,172	779	712	390	356	38	36	3,583	3,276
Research Grants	-	-	-	-	-	-	27,570	48,895	27,570	48,895
Dues and Subscriptions	6,900	7,140	4,661	4,755	3,290	2,710	198	199	15,049	14,804
Equipment Rental and Maintenance	5,703	3,137	4,421	2,542	4,669	4,924	-	-	14,793	10,603
Total Expenses	\$ 517,390	\$ 311,260	\$ 216,562	\$ 210,464	\$ 225,550	\$ 209,286	\$ 34,420	\$ 56,314	\$ 993,922	\$ 787,324

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.
Statements of Functional Expenses
For the years ended December 31, 2018 and 2017

Support Services						
	Management and General		Fund Raising		Comparative Totals	
	2018	2017	2018	2017	2018	2017
Salaries, Payroll Taxes						
Employee Benefits	\$ 25,096	\$ 20,237	\$ 34,507	\$ 31,801	\$ 59,603	\$ 52,038
Depreciation	4,877	4,138	-	-	4,877	4,138
Insurance	1,760	1,739	267	264	2,027	2,003
Meetings and Seminars	21,485	20,289	8,171	9,117	29,656	29,406
Office Expense	5,545	488	503	546	6,048	1,034
Postage	1,855	1,942	7,746	5,623	9,601	7,565
Professional Fees	31,861	26,843	11,861	11,680	43,722	38,523
Rent	1,359	1,359	1,699	1,699	3,058	3,058
Printing	1,203	191	4,283	5,167	5,486	5,358
Telephone	195	178	117	107	312	285
Research Grants	-	-	-	-	-	-
Dues and Subscriptions	1,775	1,411	1,175	3,610	2,950	5,021
Equipment Rental and Maintenance	1,474	547	482	71	1,956	618
Total Expenses	\$ 98,485	\$ 79,362	\$ 70,811	\$ 69,685	\$ 169,296	\$ 149,047

Cornelia de Lange Syndrome Foundation, Inc.
Statements of Cash Flows
For the years ended December 31, 2018 and 2017

	<u>2018</u>	<u>2017</u>
Cash flows from operating activities:		
Change in net assets	\$ (228,061)	\$ (3,686)
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	4,877	4,138
Net realized and unrealized (gains) losses	51,774	(90,736)
(Increase) decrease in:		
Promises to give	(62,379)	(37,621)
Inventories	1,179	339
Prepaid expenses	5,303	(11,607)
Increase (decrease) in:		
Accrued liabilities	(5,815)	(4,541)
Deferred revenues	7,800	-
Net cash used by operating activities	<u>(225,322)</u>	<u>(143,714)</u>
Cash flow from investing activities:		
Purchases of fixed assets	(5,080)	(8,558)
Net sales (purchases) of investments	103,078	70,402
Net cash provided by investing activities	<u>97,998</u>	<u>61,844</u>
Net decrease in cash and equivalents	(127,324)	(81,870)
Cash and equivalents, beginning of year	345,591	427,461
Cash and equivalents, end of year	<u>\$ 218,267</u>	<u>\$ 345,591</u>

See independent auditor's report and notes to financial statements

1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Description of Foundation - Cornelia de Lange Syndrome Foundation, Inc. (the Foundation) was incorporated in December 1981 as a family support organization, which exists to ensure early and accurate diagnosis of Cornelia de Lange Syndrome (CdLS), promote research into the causes and manifestations of the syndrome, and assist with a diagnosis of CdLS. From its sole office in Avon, Connecticut, Foundation Family Service Coordinators (FSCs) respond to the needs of families and health professionals by providing information about the syndrome, facilitating access to the Foundation's Clinical Advisory Board, and maintaining a national network of volunteer coordinators who extend the support services available. In addition, the Foundation operates numerous programs and produces publications to promote awareness of the syndrome and its impact on families.

The Foundation has the following programs for the years ended December 31, 2018 and 2017:

Family Support - Family Service Coordinators (FSCs) address needs of family members and health professionals in both the short and long term. FSCs answer phone calls from parents whose children have been recently diagnosed, parents needing guidance for a medical or educational decision, or families whose child has recently become ill or passed away. FSCs focus the resources of the Foundation on families by coordinating regional gatherings, supporting volunteer regional coordinators and serving as the direct point-of-contact for all family calls to the office.

Public Information and Education - The Foundation produces numerous educational publications, including a quarterly newsletter, Reaching Out, to communicate valuable information to families, friends, and health professionals nationwide.

Professional Development, Outreach and Awareness - In-house public affairs staff work to promote awareness of CdLS and the services available to professionals through the Foundation. Awareness efforts are achieved with the assistance of a nationwide network of volunteer awareness coordinators who host events, encourage media coverage of families caring for children with CdLS, and distribute Foundation-related promotional items to their local health professional community as well as to their community at-large.

Research - The Foundation supports basic science and clinical research projects to ensure that the information it provides remains the most current and accurate available.

Basis of Accounting - The financial statements of the Foundation have been prepared on the accrual basis. The significant accounting policies followed are described below to enhance the usefulness of the financial statements to the reader.

1. **SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)**

Financial Statement Presentation - Net assets, support and revenues, and expenses, are classified as with donor restrictions and without donor restrictions based upon the following criteria:

- Without donor restricted net assets represent expendable funds available for operations, which are not otherwise limited by donor restrictions. Included in without donor restricted net assets are board-designated funds which are not donor restricted and do not meet the definition of net assets with donor restrictions.
- With donor restricted net assets represent contributions and grants that are restricted by the donor either as to purpose or as to time expenditure.

Cash and Cash Equivalents - For purposes of the Statement of Cash Flows, the Foundation considers all highly liquid investments with an original maturity of three months or less to be cash equivalents.

Furniture and equipment - Furniture and equipment are capitalized at cost. Furniture and equipment are being depreciated over estimated useful lives of five to seven years using the straight-line method. Depreciation expense for the years ending December 31, 2018 and 2017 was \$4,877 and \$4,138, respectively.

Inventories - Inventories consist of fundraising items for sale through the Organization's website. They are stated at the lower of cost (first-in, first-out basis) or market.

Contributions - Contributions received as well as collectible unconditional promises to give are recognized in the period received. Grants which are transferred on a reimbursement basis are recognized as income in the period in which the application for reimbursement is submitted for payment.

Functional Allocation of Expenses - The costs of providing various programs and other activities have been summarized on a functional basis in the statement of activities. Accordingly, certain costs have been assigned to the programs and supporting services benefited based on a variety of cost allocation methods such as square footage and estimates of time and effort.

Credit Risk - The Foundation's financial instruments that are exposed to concentrations of credit risk are cash and cash equivalents. The Foundation places its cash deposits with high credit quality institutions and such deposits at times have exceeded Federal depository insurance limits. However, the Foundation has not experienced any losses in this area and management believes its cash deposits are not subject to significant credit risk.

1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)

Accounting Estimates - The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities at the date of the financial statements. Actual results may differ from those estimates.

Evaluation of Subsequent Events

The Foundation has evaluated subsequent events through July 30, 2019, the date which the financial statements were available to be issued.

Not-for-Profit Financial Statement Presentation

During 2018, Cornelia de Lange Syndrome Foundation, Inc. adopted ASU No. 2016-14 Not-for-Profit Entities (Topic 958): Presentation of Financial Statements of Not-for-Profit entities. This guidance is intended to improve the net asset classification requirements and the information presented in the financial statements and notes about a not-for-profit entity's liquidity, financial performance, and cash flows. Main provisions of this guidance include: presentation of two classes of net assets versus the previously required three; recognition of net asset without donor restrictions and net assets with donor restrictions. The guidance also enhances disclosures for board designated amounts, composition of net assets without donor restrictions, liquidity, and expenses by both their natural and functional classification.

A recap of the net asset reclassifications driven by the adoption of ASU 2016-14 as of December 31, 2017 follows:

<u>Net Assets Classifications</u>	<u>ASU 2016-14 Classifications</u>		
	<u>Without donor restrictions</u>	<u>With donor restrictions</u>	<u>Total Net Assets</u>
As previously presented:			
Unrestricted	\$1,065,883	\$ -	\$1,065,883
Temporarily Restricted	<u>-</u>	<u>137,299</u>	<u>137,299</u>
Net assets as previously presented	\$1,065,883	\$ 137,299	\$1,203,182

2. NET ASSETS

The net assets of the Foundation are considered without donor restrictions and with donor restrictions as defined by generally accepted accounting principles (See Note 1). At December 31, 2018 and 2017 the net assets of the Foundation totaled \$975,121 and \$1,203,182, respectively. In the event that the Foundation shall terminate, it shall dispose of its net assets in a manner consistent with its status as a tax-exempt entity under the Internal Revenue Code.

2. NET ASSETS (continued)

The Board of Directors of Cornelia de Lange Syndrome Foundation, Inc. has standing board policies that impact the presentation of board designated net assets. The Board of Directors has established an operating reserve with the objective of setting funds aside to be utilized in the event of financial adversity. The operating reserve balance at December 31, 2018 and 2017 was \$669,784 and \$820,951, respectively.

Net assets with donor restrictions are available for the following purposes as of December 31:

	<u>2018</u>	<u>2017</u>
21st Century Future Conferences Fund	\$ 1,606	\$ 91,206
2020 National Conference	1,000	2,923
Fixed Asset Purchase	-	5,549
Special Events	5,798	-
Time Restrictions	100,000	37,621

Net assets released from restrictions for the years ended December 31:

	<u>2018</u>	<u>2017</u>
Satisfaction of program restrictions	\$ 98,472	\$ -
Expiration of time restrictions	<u>37,621</u>	<u>-</u>
Total net assets released from restrictions	\$ 136,093	-

3. CONTRIBUTED SERVICES AND ASSETS

During the years ended December 31, 2018 and 2017, the Foundation received donated services from many individual volunteers to perform a variety of tasks that assist the Foundation in running programs and fundraising. No amounts have been recognized in the accompanying statement of activities because the criterion for recognition as contributed services under generally accepted accounting principles has not been satisfied.

Donated assets are recognized at their fair value. Contributions of stock and fixed assets are valued at fair market value at the time it was received. The Foundation received donations of stock valued at \$5,798 and \$-0- during the years ended December 31, 2018 and 2017, respectively.

4. UNCONDITIONAL PROMISES TO GIVE

Unconditional promises to give are expected to be realized in one year or less and are classified as with donor restricted net assets in the statement of activities. Unconditional promises to give amounted to \$100,000 and \$37,621 at December 31, 2018 and 2017, respectively.

Cornelia de Lange Syndrome Foundation, Inc.
Notes to the Financial Statements

5. INVESTMENTS

The Foundation investments are carried at fair value based on quoted prices in active markets (all Level 1 measurements). Accordingly, the gains or losses that result from changes in fair value are reported in the statement of activities for the period in which they occur.

	<u>2018</u>		<u>2017</u>	
	<u>Cost</u>	<u>Fair Value</u>	<u>Cost</u>	<u>Fair Value</u>
Mutual Funds	\$624,764	\$657,547	\$707,987	\$812,399

Investment income for the years ended December 31, 2018 and 2017 is as follows:

	<u>2018</u>	<u>2017</u>
Interest and dividend income	\$ 18,254	\$ 15,438
Net realized gains (losses)	19,855	103,313
Net unrealized gains (losses)	(71,629)	(12,577)
Investment expenses	<u>(7,540)</u>	<u>(8,339)</u>
Total return	\$ (41,060)	\$ 97,835

The following summarizes the relationship between carrying values and fair values of investment assets.

	<u>Cost</u>	<u>Fair Value</u>	Excess of Fair Value <u>Over Cost</u>
Balance at beginning of year	\$707,987	\$812,399	\$ 104,412
Balance at end of year	<u>624,764</u>	<u>657,547</u>	<u>32,783</u>
Unrealized gains (losses) for the year			\$ <u>(71,629)</u>

6. FINANCIAL ASSETS AND LIQUIDITY RESOURCES

The below reflects Cornelia de Lange Syndrome Foundation, Inc.'s financial assets as of the statement of financial position date, reduced by amounts that are not available for general use due to contractual or donor-imposed restrictions within one year of the statement of financial position date. Amounts that are not available also include board designated amounts that could be utilized if the Board of Directors approved the use. However, amounts already appropriated for general expenditure within one year of the statement of financial position date have not been subtracted as unavailable.

See independent auditor's report

Cornelia de Lange Syndrome Foundation, Inc.
Notes to the Financial Statements

6. FINANCIAL ASSETS AND LIQUIDITY RESOURCES (continued)

	<u>2018</u>
Financial assets, at year-end	\$ 975,814
Less those unavailable for general expenditures within one year, due to:	
Donor-imposed restrictions:	
Subject to appropriation and satisfaction of donor restrictions	5,505
Board designations:	
Amounts set aside for liquidity reserve	<u>669,784</u>
Financial assets available to meet cash needs for general expenditures within one year	\$ 300,525

The Foundation sets a goal of having financial assets on hand to meet 5 months of normal operating expenses, which are, on average approximately \$415,000. The Foundation also targets a minimum of 30 days of normal operating expenses, typically occurring at the low point of its annual cash flow cycle. As part of its liquidity management, the Foundation has a policy to structure its financial assets to be available as general expenditures, liabilities, and other obligations become due.

7. PENSION

The Foundation has a 403(b) Plan to provide retirement benefits for its employees. Employees may contribute up to the annual maximum as set periodically by the Internal Revenue Service and the Foundation will match employee contributions up to 2% of compensation. Pension expense was \$8,480 and \$7,829 for the years ended December 31, 2018 and 2017, respectively.

8. FACILITY LEASE

On April 3, 2018, the Foundation extended the terms of the current noncancelable lease agreement through March 1, 2019. The terms of the lease subsequent to March 1, 2019 are a verbal month to month lease at the current rate. The lease requires a 60 day notification upon terminating the lease. Rent expense amounted to \$33,975 for the years ended December 31, 2018 and 2017.

8. FACILITY LEASE (continued)

The following is a schedule of future minimum rental payments required under the above operating lease as of December 31, 2018.

<u>Year Ending December 31,</u>	
2019	\$ 5,663

As of the date of these financial statements, the Foundation has executed a new lease with a term of six years commencing on September 1, 2019 with a base monthly rent of \$5,046.

The following is a schedule of future minimum rental payments required under the above operating lease.

<u>Year Ending December 31,</u>	
2019	\$ 15,136
2020	55,502
2021	55,502
2022	56,925
2023	56,925
2024	58,348
2025	58,348

9. TAX STATUS

The Corporation is a nonprofit organization exempt from federal and state income taxes under Section 501(c)(3) of the Internal Revenue Code and contributions to the corporation are therefore deductible by the donor under I.R.C. Section 170(b)(1)(A)(vi).

The Organization files form 990 in the U.S. federal jurisdiction. The Organization is generally no longer subject to examination by the Internal Revenue Service for the years before 2015.

10. EVALUATION OF SUBSEQUENT EVENTS

Subsequent to December 31, 2018, the Foundation received a letter of declaration naming Cornelia de Lange Syndrome Foundation, Inc. as beneficiary of a trust. As of July 30, 2019, the Foundation has received \$428,534 and expect to receive approximately an additional \$1,000,000 within the next year.