

Cornelia de Lange
Syndrome Foundation, Inc.

FINANCIAL STATEMENTS

For the years ended
December 31, 2019 and 2018

Cornelia de Lange Syndrome Foundation, Inc.
Financial Statements
For the years ended December 31, 2019 and 2018

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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, 2019 and 2018, 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, 2019 and 2018, 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.



Bottaro, Morrill & Company, LLC

October 7, 2020

Cornelia de Lange Syndrome Foundation, Inc.

Statements of Financial Position

December 31, 2019 and 2018

	2019	2018
Assets		
Current assets:		
Cash and cash equivalents	\$ 458,579	\$ 218,267
Investments	934,580	657,547
Promises to give	876,593	100,000
Prepaid expenses	26,614	6,304
Fundraising inventory	3,188	3,659
Total current assets	<u>2,299,554</u>	<u>985,777</u>
Fixed assets:		
Equipment	71,791	76,240
Less: accumulated depreciation	(41,237)	(63,615)
Total fixed assets, net	<u>30,554</u>	<u>12,625</u>
Other assets:		
Promises to give - long term, net of discounts	118,122	-
Security deposit	-	1,230
Total assets	<u>\$ 2,448,230</u>	<u>\$ 999,632</u>
Liabilities and Net Assets		
Current liabilities:		
Accounts payable and accrued expenses	\$ 11,542	\$ 16,711
Deferred revenue	6,235	7,800
Total current liabilities	<u>17,777</u>	<u>24,511</u>
Net assets:		
Without donor restrictions:		
Undesignated funds	353,378	196,933
Board designated operating reserve	1,043,903	669,784
Total funds without donor restrictions	<u>1,397,281</u>	<u>866,717</u>
Net assets with donor restrictions	<u>1,033,172</u>	<u>108,404</u>
Total net assets	<u>2,430,453</u>	<u>975,121</u>
Total liabilities and net assets	<u>\$ 2,448,230</u>	<u>\$ 999,632</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, 2019 and 2018

	<u>2019</u>	<u>2018</u>
Changes in net assets without donor restrictions:		
Support and revenues		
Contributions and donations	\$ 801,213	\$ 316,533
Fundraising and special events	401,123	433,789
Grants	75,710	40,645
National conference	-	132,509
Interest and dividend income, net of fees	14,243	10,714
Net realized and unrealized gains (losses)	120,048	(51,774)
Net loss from asset disposals	(2,846)	-
Net assets released from restrictions	<u>102,899</u>	<u>136,093</u>
Total support and revenues	<u>1,512,390</u>	<u>1,018,509</u>
Expenses:		
Program Services		
Family support	332,287	517,390
Public information and education	204,834	216,562
Professional development, outreach and awareness	213,538	225,550
Research	<u>26,266</u>	<u>34,420</u>
Total program services	776,925	993,922
Management and general	89,716	98,485
Fundraising costs	72,326	70,811
Special events costs	<u>42,859</u>	<u>54,457</u>
Total expenses	<u>981,826</u>	<u>1,217,675</u>
Changes in net assets without donor restrictions	<u>530,564</u>	<u>(199,166)</u>
Changes in net assets with donor restrictions:		
Contributions and grants	1,027,667	107,198
Net assets released from restrictions	<u>(102,899)</u>	<u>(136,093)</u>
Changes in net assets with donor restrictions	<u>924,768</u>	<u>(28,895)</u>
Total change in net assets	\$ 1,455,332	\$ (228,061)
Net assets, beginning of year	<u>975,121</u>	<u>1,203,182</u>
Net assets, end of year	<u>\$ 2,430,453</u>	<u>\$ 975,121</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, 2019 and 2018

	Program Services									
	Family Support Program		Public Information and Education		Professional Development, Outreach and Awareness		Research		Comparative Totals	
	2019	2018	2019	2018	2019	2018	2019	2018	2019	2018
Salaries, Payroll Taxes										
Employee Benefits	\$ 246,200	\$ 238,410	\$ 147,534	\$ 147,438	\$ 185,068	\$ 175,670	\$ -	\$ 6,274	\$ 578,802	\$ 567,792
Depreciation	-	-	-	-	-	-	-	-	-	-
Insurance	2,581	1,903	1,547	1,222	1,940	1,370	-	-	6,068	4,495
Meetings and Seminars	18,487	229,175	75	908	2,159	18,052	1,033	-	21,754	248,135
Office Expense	21	27	8	217	-	-	-	-	29	244
Postage	2,314	1,619	7,924	9,655	16	10	-	-	10,254	11,284
Professional Fees	25,069	14,045	9,951	24,060	6,573	14,720	152	-	41,745	52,825
Rent	17,004	15,289	9,447	8,494	7,557	6,795	378	340	34,386	30,918
Printing	1,543	1,943	15,634	14,707	-	584	-	-	17,177	17,234
Telephone	2,875	2,376	958	779	479	390	48	38	4,360	3,583
Research Grants	-	-	-	-	-	-	24,447	27,570	24,447	27,570
Dues and Subscriptions	6,895	6,900	5,483	4,661	3,630	3,290	208	198	16,216	15,049
Equipment Rental and Maintenance	9,298	5,703	6,273	4,421	6,116	4,669	-	-	21,687	14,793
Total Expenses	\$ 332,287	\$ 517,390	\$ 204,834	\$ 216,562	\$ 213,538	\$ 225,550	\$ 26,266	\$ 34,420	\$ 776,925	\$ 993,922

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.
Statements of Functional Expenses
For the years ended December 31, 2019 and 2018

Support Services

	Management and General		Fund Raising		Comparative Totals	
	2019	2018	2019	2018	2019	2018
Salaries, Payroll Taxes						
Employee Benefits	\$ 25,891	\$ 25,096	\$ 35,587	\$ 34,507	\$ 61,478	\$ 59,603
Depreciation	6,158	4,877	-	-	6,158	4,877
Insurance	271	1,760	373	267	644	2,027
Meetings and Seminars	14,281	21,485	10,995	8,171	25,276	29,656
Office Expense	6,121	5,545	526	503	6,647	6,048
Postage	2,274	1,855	5,963	7,746	8,237	9,601
Professional Fees	26,723	31,861	7,898	11,861	34,621	43,722
Rent	1,511	1,359	1,889	1,699	3,400	3,058
Printing	1,029	1,203	7,299	4,283	8,328	5,486
Telephone	240	195	192	117	432	312
Research Grants	-	-	-	-	-	-
Dues and Subscriptions	2,573	1,775	1,252	1,175	3,825	2,950
Equipment Rental and Maintenance	2,644	1,474	352	482	2,996	1,956
Total Expenses	\$ 89,716	\$ 98,485	\$ 72,326	\$ 70,811	\$ 162,042	\$ 169,296

Cornelia de Lange Syndrome Foundation, Inc.
 Statements of Cash Flows
 For the years ended December 31, 2019 and 2018

	<u>2019</u>	<u>2018</u>
Cash flows from operating activities:		
Change in net assets	\$ 1,455,332	\$ (228,061)
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	6,158	4,877
Net realized and unrealized (gains) losses	(120,048)	51,774
(Gain) loss on disposal of property	2,846	-
Contributions of fixed assets	(827)	-
(Increase) decrease in:		
Promises to give	(894,715)	(62,379)
Prepaid expenses	(20,310)	5,303
Inventories	471	1,179
Other assets	1,230	-
Increase (decrease) in:		
Accrued liabilities	(5,169)	(5,815)
Deferred revenues	(1,565)	7,800
Net cash provided (used) by operating activities	<u>423,403</u>	<u>(225,322)</u>
Cash flow from investing activities:		
Purchases of fixed assets	(26,106)	(5,080)
Sales (purchases) of investments, net	(156,985)	103,078
Net cash provided (used) by investing activities	<u>(183,091)</u>	<u>97,998</u>
Net increase (decrease) in cash and equivalents	240,312	(127,324)
Cash and equivalents, beginning of year	218,267	345,591
Cash and equivalents, end of year	<u>\$ 458,579</u>	<u>\$ 218,267</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, 2019 and 2018:

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, 2019 and 2018 was \$6,158 and \$4,877, 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 October 7, 2020, 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, 2019 and 2018 the net assets of the Foundation totaled \$2,430,453 and \$975,121, 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.

See independent auditor's report

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, 2019 and 2018 was \$1,043,903 and \$669,784, respectively.

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

	<u>2019</u>	<u>2018</u>
21st Century Future Conferences Fund	\$ 2,006	\$ 1,606
2020 National Conference	17,490	1,000
Research Expenses	16,062	-
Special Events	2,899	5,798
Time Restrictions	\$ 994,715	\$ 100,000

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

	<u>2019</u>	<u>2018</u>
Satisfaction of program restrictions	\$ 2,899	\$ 98,472
Expiration of time restrictions	<u>100,000</u>	<u>37,621</u>
Total net assets released from restrictions	\$ 102,899	\$ 136,093

3. CONTRIBUTED SERVICES AND ASSETS

During the years ended December 31, 2019 and 2018, 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 \$-0- and \$5,798 during the years ended December 31, 2019 and 2018, 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 \$994,715 and \$100,000 at December 31, 2019 and 2018, respectively.

5. PLEDGES RECEIVABLE

The Foundation has been named a recipient of a Trust. The pledges receivable at December 31, 2019 represent unconditional promises to give as follows:

Unconditional promises to give	\$ 996,593
Less unamortized discount	<u>(1,878)</u>
Net pledges receivable	994,715

Total pledges receivable are due as follows:

Less than one year	\$ 876,593
One to five years	<u>118,122</u>
Total pledges receivable	994,715

Pledges receivable with due dates extending beyond one year are discounted using Treasury bill rates for similar term investments. The applicable rate at December 31, 2019 was 1.5%. Amortization of the discount is reported in the Statement of Activities as interest income.

6. INVESTMENTS

The Foundation investments in marketable securities with readily determinable fair values and all investments in debt securities are reported at their fair values based on quoted prices in active markets (all Level 1 measurements) in the statement of financial position. Unrealized gains and losses are included in the change in net assets. investment income and gains restricted by a donor are reported as increases in unrestricted net assets if the restrictions are met (either by passage of time or by use) in the reporting period in which the income and gains are recognized.

	<u>2019</u>		<u>2018</u>	
	<u>Cost</u>	<u>Fair Value</u>	<u>Cost</u>	<u>Fair Value</u>
Mutual Funds	\$779,547	\$934,580	\$623,482	\$657,547

Investment income for the years ended December 31, 2019 and 2018 is as follows:

	<u>2019</u>	<u>2018</u>
Interest and dividend income	\$ 22,370	\$ 18,254
Net realized gains (losses)	(920)	19,855
Net unrealized gains (losses)	120,968	(71,629)
Investment expenses	<u>(8,127)</u>	<u>(7,540)</u>
Total return	\$ 134,291	\$ (41,060)

6. INVESTMENTS (continued)

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	\$623,482	\$657,547	\$ 34,065
Balance at end of year	<u>779,547</u>	<u>934,580</u>	<u>155,033</u>
Unrealized gains (losses) for the year			\$ <u>120,968</u>

7. 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.

	<u>2019</u>
Financial assets, at year-end	\$ 2,387,874
Less those unavailable for general expenditures within one year, due to:	
Donor-imposed restrictions:	
Subject to time restrictions more than a year	118,122
Board designations:	
Amounts set aside for liquidity reserve	<u>1,043,903</u>
Financial assets available to meet cash needs for general expenditures within one year	\$ 1,225,849

The Foundation sets a goal of having financial assets on hand to meet 5 months of normal operating expenses, which are, on average approximately \$400,000. 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.

8. 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 \$9,336 and \$8,480 for the years ended December 31, 2019 and 2018, respectively.

9. FACILITY LEASE

On April 3, 2018, the Foundation extended the terms of the noncancelable lease agreement through March 1, 2019 and then as a verbal month to month agreement through August 31, 2019. Effective September 1, 2019, the Foundation entered a new lease agreement which expires on August 31, 2025. Rent expense amounted to \$37,787 and \$33,975 for the years ended December 31, 2019 and 2018, respectively.

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

<u>Year Ending December 31,</u>	
2020	\$ 55,502
2021	55,890
2022	56,925
2023	57,313
2024	58,348
2025	42,435

10. 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 2016.

11. EVALUATION OF SUBSEQUENT EVENTS

On April 23, 2020, Cornelia de Lange Syndrome Foundation, Inc. was granted a loan from a bank, in the aggregate amount of \$122,197, pursuant to the Paycheck Protection Program (the "PPP") under Division A, Title 1 of the CARES Act, which was enacted March 27, 2020.

11. EVALUATION OF SUBSEQUENT EVENTS (continued)

Funds from the loan may only be used for payroll costs, costs used to continue group healthcare benefits, mortgage payments, rent, utilities, and interest on other debt obligations incurred before February 15, 2020. The Company intends to use the entire loan proceeds for qualifying expenses. Under the terms of the PPP, certain amounts or all of the loan may be forgiven if the funds are used for qualifying expenses as described in the CARES Act.