

Cornelia de Lange
Syndrome Foundation, Inc.

FINANCIAL STATEMENTS

For the years ended
December 31, 2020 and 2019

Cornelia de Lange Syndrome Foundation, Inc.
Financial Statements
For the years ended December 31, 2020 and 2019

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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, 2020 and 2019, 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, 2020 and 2019, 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.

Other Matters

Change in Accounting Principles - As discussed in Note 1 to the financial statements, in 2020 Cornelia de Lange Syndrome Foundation, Inc. adopted new accounting guidance for contributions received. Our opinion is not modified with respect to these matters.



Bottaro, Morrill & Company, LLC

August 2, 2021

Cornelia de Lange Syndrome Foundation, Inc.

Statements of Financial Position

December 31, 2020 and 2019

	2020	2019
Assets		
Current assets:		
Cash and cash equivalents	\$ 694,241	\$ 458,579
Investments	1,978,645	934,580
Promises to give	120,000	876,593
Prepaid expenses	7,860	26,614
Fundraising inventory	2,863	3,188
Total current assets	<u>2,803,609</u>	<u>2,299,554</u>
Fixed assets:		
Equipment	71,791	71,791
Less: accumulated depreciation	(48,613)	(41,237)
Total fixed assets, net	<u>23,178</u>	<u>30,554</u>
Other assets:		
Promises to give - long term, net of discounts	<u>-</u>	<u>118,122</u>
Total assets	<u>\$ 2,826,787</u>	<u>\$ 2,448,230</u>
Liabilities and Net Assets		
Current liabilities:		
Accounts payable and accrued expenses	\$ 61,904	\$ 11,542
Deferred revenue	4,468	6,235
Total current liabilities	<u>66,372</u>	<u>17,777</u>
Net assets:		
Without donor restrictions:		
Undesignated funds	582,880	353,378
Board designated operating reserve	2,013,853	1,043,903
Total funds without donor restrictions	<u>2,596,733</u>	<u>1,397,281</u>
Net assets with donor restrictions	<u>163,682</u>	<u>1,033,172</u>
Total net assets	<u>2,760,415</u>	<u>2,430,453</u>
Total liabilities and net assets	<u>\$ 2,826,787</u>	<u>\$ 2,448,230</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, 2020 and 2019

	<u>2020</u>	<u>2019</u>
Changes in net assets without donor restrictions:		
Support and revenues		
Contributions and donations	\$ 459,105	\$ 801,213
Fundraising and special events	285,902	401,123
Grants	103,908	75,710
National conference	12,581	-
Interest and dividend income, net of fees	22,078	14,243
Net realized and unrealized gains (losses)	256,433	120,048
Net loss from asset disposals	-	(2,846)
Paycheck protection program grant	122,197	-
Net assets released from restrictions	<u>890,593</u>	<u>102,899</u>
Total support and revenues	<u>2,152,797</u>	<u>1,512,390</u>
Expenses:		
Program Services		
Family support	368,291	332,287
Public information and education	195,609	204,834
Professional development, outreach and awareness	208,851	213,538
Research	153	26,266
Total program services	<u>772,904</u>	<u>776,925</u>
Management and general	85,215	89,716
Fundraising costs	74,743	72,326
Special events costs	<u>20,483</u>	<u>42,859</u>
Total expenses	<u>953,345</u>	<u>981,826</u>
Changes in net assets without donor restrictions	<u>1,199,452</u>	<u>530,564</u>
Changes in net assets with donor restrictions:		
Contributions and grants	21,103	1,027,667
Net assets released from restrictions	<u>(890,593)</u>	<u>(102,899)</u>
Changes in net assets with donor restrictions	<u>(869,490)</u>	<u>924,768</u>
Total change in net assets	\$ 329,962	\$ 1,455,332
Net assets, beginning of year	<u>2,430,453</u>	<u>975,121</u>
Net assets, end of year	<u>\$ 2,760,415</u>	<u>\$ 2,430,453</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, 2020 and 2019

Program Services										
	Family Support Program		Public Information and Education		Professional Development, Outreach and Awareness		Research		Comparative Totals	
	2020	2019	2020	2019	2020	2019	2020	2019	2020	2019
Salaries, Payroll Taxes										
Employee Benefits	\$ 269,400	\$ 246,200	\$ 139,690	\$ 147,534	\$ 177,495	\$ 185,068	\$ -	\$ -	\$ 586,585	\$ 578,802
Depreciation	-	-	-	-	-	-	-	-	-	-
Insurance	2,608	2,581	1,352	1,547	1,718	1,940	-	-	5,678	6,068
Meetings and Seminars	32,342	18,487	-	75	-	2,159	-	1,033	32,342	21,754
Office Expense	1,931	21	1,423	8	858	-	-	-	4,212	29
Postage	1,574	2,314	6,448	7,924	39	16	-	-	8,061	10,254
Professional Fees	19,737	25,069	11,897	9,951	4,524	6,573	-	152	36,158	41,745
Rent	22,781	17,004	11,812	9,447	15,009	7,557	-	378	49,602	34,386
Printing	330	1,543	11,780	15,634	-	-	-	-	12,110	17,177
Telephone	2,774	2,875	925	958	462	479	-	48	4,161	4,360
Research Grants	-	-	-	-	-	-	-	24,447	-	24,447
Dues and Subscriptions	5,650	6,895	3,306	5,483	3,018	3,630	153	208	12,127	16,216
Equipment Rental and Maintenance	9,164	9,298	6,976	6,273	5,728	6,116	-	-	21,868	21,687
Total Expenses	\$ 368,291	\$ 332,287	\$ 195,609	\$ 204,834	\$ 208,851	\$ 213,538	\$ 153	\$ 26,266	\$ 772,904	\$ 776,925

See independent auditor's report and notes to the financial statements

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.
Statements of Functional Expenses
For the years ended December 31, 2020 and 2019

Support Services							
	Management and General		Fund Raising		Comparative Totals		
	2020	2019	2020	2019	2020	2019	
Salaries, Payroll Taxes							
Employee Benefits	\$ 33,162	\$ 25,891	\$ 36,610	\$ 35,587	\$ 69,772	\$ 61,478	
Depreciation	7,376	6,158	-	-	7,376	6,158	
Insurance	322	271	354	373	676	644	
Meetings and Seminars	3,704	14,281	2,409	10,995	6,113	25,276	
Office Expense	591	6,121	129	526	720	6,647	
Postage	2,127	2,274	5,510	5,963	7,637	8,237	
Professional Fees	25,678	26,723	10,384	7,898	36,062	34,621	
Rent	2,804	1,511	3,096	1,889	5,900	3,400	
Printing	1,625	1,029	13,027	7,299	14,652	8,328	
Telephone	232	240	231	192	463	432	
Research Grants	-	-	-	-	-	-	
Dues and Subscriptions	3,943	2,573	2,536	1,252	6,479	3,825	
Equipment Rental and Maintenance	3,651	2,644	457	352	4,108	2,996	
Total Expenses	\$ 85,215	\$ 89,716	\$ 74,743	\$ 72,326	\$ 159,958	\$ 162,042	

Cornelia de Lange Syndrome Foundation, Inc.
Statements of Cash Flows
For the years ended December 31, 2020 and 2019

	<u>2020</u>	<u>2019</u>
Cash flows from operating activities:		
Change in net assets	\$ 329,962	\$ 1,455,332
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	7,376	6,158
Net realized and unrealized (gains) losses	(256,433)	(120,048)
Contributions of investments	(647,436)	-
(Gain) loss on disposal of property	-	2,846
Contributions of fixed assets	-	(827)
(Increase) decrease in:		
Promises to give	874,715	(894,715)
Prepaid expenses	18,754	(20,310)
Inventories	325	471
Other assets	-	1,230
Increase (decrease) in:		
Accrued liabilities	50,362	(5,169)
Deferred revenues	(1,767)	(1,565)
Net cash provided by operating activities	<u>375,858</u>	<u>423,403</u>
Cash flow from investing activities:		
Purchases of fixed assets	-	(26,106)
Sales (purchases) of investments, net	(140,196)	(156,985)
Net cash used by investing activities	<u>(140,196)</u>	<u>(183,091)</u>
Net increase in cash and equivalents	235,662	240,312
Cash and equivalents, beginning of year	458,579	218,267
Cash and equivalents, end of year	<u>\$ 694,241</u>	<u>\$ 458,579</u>

See independent auditor's report and notes to financial statements

Cornelia de Lange Syndrome Foundation, Inc.
Notes to the 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, 2020 and 2019:

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 in accordance with generally accepted accounting principles (GAAP) in the United States of America.

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

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

Adoption of Accounting Standards Update - During the year ended December 31, 2020, the Foundation adopted Accounting Standards Update (ASU) 2018-08, Accounting Guidance for Contributions Received and Made. This ASU was issued to clarify accounting guidance for contributions received and made. The amendments to this ASU assists entities in 1) evaluating whether transactions should be accounted for as contributions (nonreciprocal transactions) within the scope of Topic 958, Not-for-Profit Entities, or as exchange (reciprocal) transactions subject to other guidance and 2) determining if the contribution is conditional. The adoption of ASU 2018-08 had no effect on the Foundation's financial statements as of the year ended December 31, 2020.

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, 2020 and 2019 was \$7,376 and \$6,158, 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.

See independent auditor's report

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

1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)

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.

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 August 2, 2021, the date which the financial statements were available to be issued.

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, 2020 and 2019 the net assets of the Foundation totaled \$2,760,415 and \$2,430,453, 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.

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, 2020 and 2019 was \$2,013,853 and \$1,043,903, respectively.

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

	<u>2020</u>	<u>2019</u>
21st Century Future Conferences Fund	\$ 2,006	\$ 2,006
2022 National Conference	12,582	17,490
Research Expenses	19,062	16,062
Special Events	10,032	2,899
Time Restrictions	120,000	994,715

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

	<u>2020</u>	<u>2019</u>
Satisfaction of program restrictions	\$ 13,999	\$ 2,899
Expiration of time restrictions	<u>876,594</u>	<u>100,000</u>
Total net assets released from restrictions	\$ 890,593	\$ 102,899

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

3. CONTRIBUTED SERVICES AND ASSETS

During the years ended December 31, 2020 and 2019, 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 \$647,436 and \$-0- during the years ended December 31, 2020 and 2019, respectively.

4. UNCONDITIONAL PROMISES TO GIVE

The Foundation anticipates collection of unconditional promises to give as follows:

	<u>2020</u>	<u>2019</u>
Due in less than one year	\$ 120,000	\$ 876,593
Due in one to five years	<u>-</u>	<u>120,000</u>
	120,000	996,593
Less discount to present value	<u>-</u>	<u>(1,878)</u>
Total	\$ 120,000	\$ 994,715

Unconditional promises to give 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 0.1%. Amortization of the discount is reported in the Statement of Activities as interest income.

5. 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>2020</u>		<u>2019</u>	
	<u>Cost</u>	<u>Fair Value</u>	<u>Cost</u>	<u>Fair Value</u>
Mutual Funds	\$1,565,210	\$1,978,645	\$779,547	\$934,580

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

5. INVESTMENTS (continued)

Investment income for the years ended December 31, 2020 and 2019 is as follows:

	<u>2020</u>	<u>2019</u>
Interest and dividend income	\$ 34,882	\$ 22,370
Net realized gains (losses)	(1,969)	(920)
Net unrealized gains (losses)	258,402	120,968
Investment expenses	<u>(12,804)</u>	<u>(8,127)</u>
Total return	\$ 278,511	\$ 134,291

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

	<u>Cost</u>	<u>Fair Value</u>	<u>Excess of Fair Value Over Cost</u>
Balance at beginning of year	\$ 779,547	\$ 934,580	\$ 155,033
Balance at end of year	<u>\$1,565,210</u>	<u>\$ 1,978,645</u>	<u>413,435</u>
Unrealized gains (losses) for the year			\$ <u>258,402</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.

Financial assets, at year-end	<u>2020</u> \$ 2,792,886
Less those unavailable for general expenditures within one year, due to:	
Subject to donor-imposed restrictions:	43,682
Board designations:	
Amounts set aside for liquidity reserve	<u>2,013,853</u>
Financial assets available to meet cash needs for general expenditures within one year	\$ 735,351

See independent auditor's report

6. FINANCIAL ASSETS AND LIQUIDITY RESOURCES (continued)

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.

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 \$6,712 and \$9,336 for the years ended December 31, 2020 and 2019, respectively.

8. 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 \$55,502 and \$37,787 for the years ended December 31, 2020 and 2019, respectively.

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

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

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 2017.

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

10. Payroll Protection Program

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. Under the program terms, PPP loans are forgiven and recognized as grant revenue if the loan proceeds are used for payroll costs and maintaining employee headcount, costs used to continue group healthcare benefits, mortgage payments, rent, utilities, and interest on other debt obligations incurred before February 15, 2020. The Foundation met this criteria for forgiveness and submitted its loan forgiveness application prior to December 31, 2020 which was granted full forgiveness of the loan on February 18, 2021. Therefore, the amount of \$122,197 was recognized as grant revenue for the year ending December 31, 2020.

The Foundation also received a second PPP loan in the amount of \$122,432 on February 3, 2021. The new loan is subject to the same terms as the first loan under the PPP Flexibility Act of 2020.