

Cornelia de Lange
Syndrome Foundation, Inc.

FINANCIAL STATEMENTS

For the years ended
December 31, 2021 and 2020

Cornelia de Lange Syndrome Foundation, Inc.
Financial Statements
For the years ended December 31, 2021 and 2020

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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, 2021 and 2020, 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.

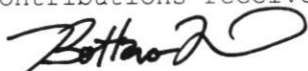
We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

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, 2021 and 2020, 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

October 12, 2022

Cornelia de Lange Syndrome Foundation, Inc.

Statements of Financial Position

December 31, 2021 and 2020

	2021	2020
Assets		
Current assets:		
Cash and cash equivalents	\$ 626,437	\$ 694,241
Investments	2,432,196	1,978,645
Promises to give	103,000	120,000
Employee retention tax credit receivable	64,721	-
Prepaid expenses	31,947	7,860
Fundraising inventory	2,578	2,863
Total current assets	<u>3,260,879</u>	<u>2,803,609</u>
Fixed assets:		
Equipment	73,320	71,791
Less: accumulated depreciation	(55,016)	(48,613)
Total fixed assets, net	<u>18,304</u>	<u>23,178</u>
Other assets:		
Promises to give - long term, net discount \$1,253	<u>98,959</u>	<u>-</u>
Total assets	<u>\$ 3,378,142</u>	<u>\$ 2,826,787</u>
Liabilities and Net Assets		
Current liabilities:		
Accounts payable and accrued expenses	\$ 66,273	\$ 61,904
Deferred revenue	782	4,468
Total current liabilities	<u>67,055</u>	<u>66,372</u>
Net assets:		
Without donor restrictions:		
Undesignated funds	560,752	582,880
Board designated operating reserve	2,503,707	2,013,853
Total funds without donor restrictions	<u>3,064,459</u>	<u>2,596,733</u>
Net assets with donor restrictions	<u>246,628</u>	<u>163,682</u>
Total net assets	<u>3,311,087</u>	<u>2,760,415</u>
Total liabilities and net assets	<u>\$ 3,378,142</u>	<u>\$ 2,826,787</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, 2021 and 2020

	<u>2021</u>	<u>2020</u>
Changes in net assets without donor restrictions:		
Support and revenues		
Contributions and donations	\$ 480,642	\$ 459,105
Fundraising and special events	399,333	285,902
Grants	75,817	103,908
National conference	-	12,581
Interest and dividend income, net of fees	25,288	22,078
Net realized and unrealized gains (losses)	255,983	256,433
Paycheck protection program grant	123,428	122,197
Employee retention tax credit grant	64,721	-
Net assets released from restrictions	10,032	890,593
Total support and revenues	<u>1,435,244</u>	<u>2,152,797</u>
Expenses:		
Program Services		
Family support	333,244	368,291
Public information and education	202,272	195,609
Professional development, outreach and awareness	207,719	208,851
Research	-	153
Total program services	<u>743,235</u>	<u>772,904</u>
Management and general	91,198	85,215
Fundraising costs	86,997	74,743
Special events costs	46,088	20,483
Total expenses	<u>967,518</u>	<u>953,345</u>
Changes in net assets without donor restrictions	<u>467,726</u>	<u>1,199,452</u>
Changes in net assets with donor restrictions:		
Contributions and grants	92,978	21,103
Net assets released from restrictions	(10,032)	(890,593)
Changes in net assets with donor restrictions	<u>82,946</u>	<u>(869,490)</u>
Total change in net assets	\$ 550,672	\$ 329,962
Net assets, beginning of year	2,760,415	2,430,453
Net assets, end of year	<u>\$ 3,311,087</u>	<u>\$ 2,760,415</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, 2021 and 2020

Program Services										
	Family Support Program		Public Information and Education		Professional Development, Outreach and Awareness		Research		Comparative Totals	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Salaries, Payroll Taxes Employee Benefits	\$ 255,334	\$ 269,400	\$ 143,339	\$ 139,690	\$ 173,843	\$ 177,495	\$ -	\$ -	\$ 572,516	\$ 586,585
Depreciation	2,453	-	1,377	-	1,670	\$ -	-	-	\$ 5,500	-
Insurance	2,547	2,608	1,430	1,352	1,734	\$ 1,718	-	-	\$ 5,711	5,678
Meetings and Seminars	1,844	32,342	-	-	-	\$ -	-	-	\$ 1,844	32,342
Office Expense	4,628	1,931	4,133	1,423	-	\$ 858	-	-	\$ 8,761	4,212
Postage	1,938	1,574	6,657	6,448	138	\$ 39	-	-	\$ 8,733	8,061
Professional Fees	19,265	19,737	7,850	11,897	4,746	\$ 4,524	-	-	\$ 31,861	36,158
Rent	22,238	22,781	12,484	11,812	15,141	\$ 15,009	-	-	\$ 49,863	49,602
Printing	4,517	330	14,812	11,780	95	\$ -	-	-	\$ 19,424	12,110
Telephone	4,320	2,774	113	925	170	\$ 462	-	-	\$ 4,603	4,161
Dues and Subscriptions	3,971	5,650	4,357	3,306	3,245	\$ 3,018	-	153	\$ 11,573	12,127
Interest	-	-	-	-	-	-	-	-	-	-
Equipment Rental and Maintenance	10,189	9,164	5,720	6,976	6,937	\$ 5,728	-	-	\$ 22,846	21,868
Total Expenses	\$ 333,244	\$ 368,291	\$ 202,272	\$ 195,609	\$ 207,719	\$ 208,851	\$ -	\$ 153	\$ 743,235	\$ 772,904

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, 2021 and 2020

Support Services

	Management and General		Fund Raising		Comparative Totals	
	2021	2020	2021	2020	2021	2020
Salaries, Payroll Taxes Employee Benefits	\$ 44,194	\$ 33,162	\$ 49,833	\$ 36,610	\$ 94,027	\$ 69,772
Depreciation	425	7,376	479	-	904	7,376
Insurance	441	322	497	354	938	676
Meetings and Seminars	3,605	3,704	701	2,409	4,306	6,113
Office Expense	4,431	591	1,467	129	5,898	720
Postage	2,809	2,127	3,483	5,510	6,292	7,637
Professional Fees	23,062	25,678	10,527	10,384	33,589	36,062
Rent	3,849	2,804	4,340	3,096	8,189	5,900
Printing	427	1,625	10,293	13,027	10,720	14,652
Telephone	113	232	170	231	283	463
Dues and Subscriptions	5,083	3,943	3,312	2,536	8,395	6,479
Interest	996	-	-	-	996	-
Equipment Rental and Maintenance	1,763	3,651	1,895	457	3,658	4,108
Total Expenses	\$ 91,198	\$ 85,215	\$ 86,997	\$ 74,743	\$ 178,195	\$ 159,958

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

Cornelia de Lange Syndrome Foundation, Inc.
 Statements of Cash Flows
 For the years ended December 31, 2021 and 2020

	<u>2021</u>	<u>2020</u>
Cash flows from operating activities:		
Change in net assets	\$ 550,672	\$ 329,962
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	6,403	7,376
Net realized and unrealized (gains) losses	(255,983)	(256,433)
Contributions of investments	(8,755)	(647,436)
(Increase) decrease in:		
Promises to give	(81,959)	874,715
Prepaid expenses	(24,087)	18,754
Inventories	285	325
Employee retention tax credit receivable	(64,721)	-
Increase (decrease) in:		
Accrued liabilities	4,369	50,362
Deferred revenues	(3,686)	(1,767)
Net cash provided by operating activities	<u>122,538</u>	<u>375,858</u>
Cash flow from investing activities:		
Purchases of fixed assets	(1,529)	-
Sales (purchases) of investments, net	(188,813)	(140,196)
Net cash used by investing activities	<u>(190,342)</u>	<u>(140,196)</u>
Net increase (decrease) in cash and equivalents	(67,804)	235,662
Cash and equivalents, beginning of year	694,241	458,579
Cash and equivalents, end of year	<u>\$ 626,437</u>	<u>\$ 694,241</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, 2021 and 2020:

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.

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, 2021 and 2020, respectively.

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, 2021 and 2020 was \$6,403 and \$7,376, 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.

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 October 12, 2022, 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, 2021 and 2020 the net assets of the Foundation totaled \$3,311,087 and \$2,760,415, 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, 2021 and 2020 was \$2,503,707 and \$2,013,853, respectively.

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

	<u>2021</u>	<u>2020</u>
21st Century Future Conferences Fund	\$ 2,006	\$ 2,006
2022 National Conference	25,767	12,582
Research Expenses	42,249	19,062
Special Events	1,395	10,032
Time Restrictions	175,211	120,000

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

	<u>2021</u>	<u>2020</u>
Satisfaction of program restrictions	\$ 10,032	\$ 13,999
Expiration of time restrictions	<u>-</u>	<u>876,594</u>
Total net assets released from restrictions	\$ 10,032	\$ 890,593

See independent auditor's report

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

3. CONTRIBUTED SERVICES AND ASSETS

During the years ended December 31, 2021 and 2020, 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 \$8,755 and \$647,436 during the years ended December 31, 2021 and 2020, respectively.

4. UNCONDITIONAL PROMISES TO GIVE

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

	<u>2021</u>	<u>2020</u>
Due in less than one year	\$ 103,000	\$ 120,000
Due in one to five years	<u>100,213</u>	<u>-</u>
	203,212	120,000
Less discount to present value	<u>1,253</u>	<u>-</u>
Total	\$ 201,960	\$ 120,000

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, 2021 was 1.25%. 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>2021</u>		<u>2020</u>	
	<u>Cost</u>	<u>Fair Value</u>	<u>Cost</u>	<u>Fair Value</u>
Mutual Funds	\$1,792,044	\$2,432,196	\$1,565,210	\$1,978,645

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

5. INVESTMENTS (continued)

Investment income for the years ended December 31, 2021 and 2020 is as follows:

	<u>2021</u>	<u>2020</u>
Interest and dividend income	\$ 40,092	\$ 34,882
Net realized gains (losses)	29,266	(1,969)
Net unrealized gains (losses)	226,717	258,402
Investment expenses	<u>(14,804)</u>	<u>(12,804)</u>
Total return	\$ 281,271	\$ 278,511

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	\$1,565,210	\$ 1,978,645	\$ 413,435
Balance at end of year	<u>\$1,792,044</u>	<u>\$ 2,432,196</u>	<u>640,152</u>
Unrealized gains (losses) for the year			\$ <u>226,717</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>2021</u> \$ 3,325,313
Less those unavailable for general expenditures within one year, due to:	
Promise to give	98,959
Subject to donor-imposed restrictions:	71,417
Board designations:	
Amounts set aside for liquidity reserve	<u>2,503,707</u>
Financial assets available to meet cash needs for general expenditures within one year	\$ 651,230

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 3% of compensation. Pension expense was \$13,077 and \$6,712 for the years ended December 31, 2021 and 2020, 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 \$58,052 and \$55,502 for the years ended December 31, 2021 and 2020, respectively.

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

<u>Year Ending December 31,</u>	
2022	\$ 56,925
2023	57,313
2024	58,348
2025	42,435
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 2018.

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, and was granted full forgiveness on December 2, 2021.

11. Employee Retention Tax Credit Receivable

Under the recently enacted American Rescue Plan Act and previously under the Consolidated Appropriations Act, the Organization became eligible to apply for the employee retention tax credit, a provision of the CARES Act. It can be claimed through December 31, 2021 by eligible employers who retained employees during the COVID-19 pandemic. Employers are eligible for the credit if they experienced either full or partial suspension of operations during any calendar quarter because of governmental orders due to the pandemic or a significant decline in gross receipts based on comparing quarterly revenue results for 2020 and/or 2021 with the comparable quarter in 2019. The Employee Retention Tax Credit is a refundable credit that the Organization can claim on qualified wages paid to employees, including certain health insurance costs. The Organization filed for a refund claim of \$64,721 with the Internal Revenue Service for the year ended December 31, 2021.