

Cornelia de Lange
Syndrome Foundation, Inc.

FINANCIAL STATEMENTS

For the year ended
December 31, 2022
With Summarized Information for 2021

Cornelia de Lange Syndrome Foundation, Inc.
Financial Statements
For the year ended December 31, 2022
with Summarized Information for 2021

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BOTTARO, MORRILL & COMPANY, LLC

Certified Public Accountants

Independent Auditor's Report

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

Opinion

We have audited the accompanying financial statements of Cornelia de Lange Syndrome Foundation, Inc. (a nonprofit organization), which comprise the statement of financial position as of December 31, 2022, and the related statements of activities, functional expenses and cash flows for the year then ended, and the related notes to the financial statements.

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, 2022, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of Cornelia de Lange Syndrome Foundation, Inc. and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about Cornelia de Lange Syndrome Foundation, Inc.'s ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial

likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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 Cornelia de Lange Syndrome Foundation, Inc.'s internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about Cornelia de Lange Syndrome Foundation, Inc.'s ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

Report on Summarized Comparative Information

We have previously audited Cornelia de Lange Syndrome Foundation, Inc.'s 2021 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated October 12, 2022. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2021, is consistent, in all material respects, with the audited financial statements from which it has been derived.



Bottaro, Morrill & Company, LLC

November 29, 2023

Cornelia de Lange Syndrome Foundation, Inc.
Statement of Financial Position
December 31, 2022
With Summarized Financial Information for 2021

	2022	2021
Assets		
Current assets:		
Cash and cash equivalents	\$ 700,357	\$ 626,437
Investments	2,031,698	2,432,196
Promises to give	-	103,000
Prepaid expenses	18,164	31,947
Fundraising inventory	2,507	2,578
Employee retention tax credit receivable	64,721	64,721
Total current assets	<u>2,817,447</u>	<u>3,260,879</u>
Fixed assets:		
Equipment	73,320	73,320
Less: accumulated depreciation	(61,218)	(55,016)
Total fixed assets, net	<u>12,102</u>	<u>18,304</u>
Other assets:		
Promises to give - long term, net discount \$1,253	98,959	98,959
Right-of-use asset, net	153,585	-
Total other assets	<u>252,544</u>	<u>98,959</u>
Total assets	<u>\$ 3,082,093</u>	<u>\$ 3,378,142</u>
Liabilities and Net Assets		
Current liabilities:		
Accounts payable and accrued expenses	\$ 46,213	\$ 66,273
Lease liability	55,612	-
Deferred revenue	782	782
Total current liabilities	<u>102,607</u>	<u>67,055</u>
Lease liability - long-term	<u>99,690</u>	<u>-</u>
Net assets:		
Without donor restrictions:		
Undesignated funds	583,296	560,752
Board designated operating reserve	2,116,837	2,503,707
Total funds without donor restrictions	<u>2,700,133</u>	<u>3,064,459</u>
Net assets with donor restrictions	<u>179,663</u>	<u>246,628</u>
Total net assets	<u>2,879,796</u>	<u>3,311,087</u>
Total liabilities and net assets	<u>\$ 3,082,093</u>	<u>\$ 3,378,142</u>

See independent auditor's report and notes to financial statements

Cornelia de Lange Syndrome Foundation, Inc.
Statement of Activities
For the year ended December 31, 2022
With Summarized Financial Information for 2021

	<u>2022</u>	<u>2021</u>
Changes in net assets without donor restrictions:		
Support and revenues		
Contributions and donations	\$ 573,263	\$ 480,642
Fundraising and special events	371,080	399,333
Grants	93,755	75,817
National conference	28,754	-
Interest and dividend income, net of fees	32,915	25,288
Net realized and unrealized gains (losses)	(429,282)	255,983
Paycheck protection program grant	-	123,428
Employee retention tax credit grant	-	64,721
Net assets released from restrictions	85,300	10,032
Total support and revenues	<u>755,785</u>	<u>1,435,244</u>
Expenses:		
Program Services		
Family support	415,690	333,244
Public information and education	220,609	202,272
Professional development, outreach and awareness	206,768	207,719
Total program services	<u>843,067</u>	<u>743,235</u>
Management and general	106,318	91,198
Fundraising costs	126,164	86,997
Special events costs	44,562	46,088
Total expenses	<u>1,120,111</u>	<u>967,518</u>
Changes in net assets without donor restrictions	<u>(364,326)</u>	<u>467,726</u>
Changes in net assets with donor restrictions:		
Contributions and grants	18,335	92,978
Net assets released from restrictions	(85,300)	(10,032)
Changes in net assets with donor restrictions	<u>(66,965)</u>	<u>82,946</u>
Total change in net assets	\$ (431,291)	\$ 550,672
Net assets, beginning of year	<u>3,311,087</u>	<u>2,760,415</u>
Net assets, end of year	<u>\$ 2,879,796</u>	<u>\$ 3,311,087</u>

See independent auditor's report and notes to financial statements

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.
Statement of Functional Expenses
For the year ended December 31, 2022
With Summarized Financial Information for 2021

	Program Services				
	Family Support Program	Public Information and Education	Professional Development, Outreach and Awareness	Comparative Totals	
	2022	2022	2022	2022	2021
Salaries, Payroll Taxes Employee Benefits	\$ 283,360	\$ 167,599	\$ 181,528	\$ 632,487	\$ 572,516
Depreciation	2,340	1,384	1,501	5,225	5,500
Insurance	2,547	1,506	1,631	5,684	5,711
Meetings and Seminars	64,814	201	-	65,015	1,844
Office Expense	6,601	2,373	-	8,974	8,761
Postage	2,061	8,800	-	10,861	8,733
Professional Fees	18,847	2,487	2,228	23,562	31,861
Rent	22,739	13,450	14,568	50,757	49,863
Printing	2,536	16,564	-	19,100	19,424
Telephone	2,586	1,529	1,656	5,771	4,603
Dues and Subscriptions	69	2,699	1,471	4,239	11,573
Interest	-	-	-	-	-
Equipment Rental and Maintenance	7,190	2,017	2,185	11,392	22,846
Total Expenses	\$ 415,690	\$ 220,609	\$ 206,768	\$ 843,067	\$ 743,235

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

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.
Statement of Functional Expenses
For the year ended December 31, 2022
With Summarized Financial Information for 2021

<u>Support Services</u>				
	<u>Management and General</u>	<u>Fund Raising</u>	<u>Comparative Totals</u>	
	<u>2022</u>	<u>2022</u>	<u>2022</u>	<u>2021</u>
Salaries, Payroll Taxes				
Employee Benefits	\$ 46,679	\$ 72,849	\$ 119,528	\$ 94,027
Depreciation	383	595	\$ 978	\$ 904
Insurance	416	655	\$ 1,071	\$ 938
Meetings and Seminars	7,928	7,461	\$ 15,389	\$ 4,306
Office Expense	7,794	6,464	\$ 14,258	\$ 5,898
Postage	2,219	2,568	\$ 4,787	\$ 6,292
Professional Fees	30,978	17,963	\$ 48,941	\$ 33,589
Rent	3,718	5,846	\$ 9,564	\$ 8,189
Printing	618	7,062	\$ 7,680	\$ 10,720
Telephone	423	665	\$ 1,088	\$ 283
Dues and Subscriptions	4,604	3,159	\$ 7,763	\$ 8,395
Interest	-	-	\$ -	\$ 996
Equipment Rental and Maintenance	558	877	\$ 1,435	\$ 3,658
Total Expenses	<u>\$ 106,318</u>	<u>\$ 126,164</u>	<u>\$ 232,482</u>	<u>\$ 178,195</u>

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

Cornelia de Lange Syndrome Foundation, Inc.
Statement of Cash Flows
For the year ended December 31, 2022
With Summarized Financial Information for 2021

	<u>2022</u>	<u>2021</u>
Cash flows from operating activities:		
Change in net assets	\$ (431,291)	\$ 550,672
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	6,203	6,403
Net realized and unrealized (gains) losses	429,282	(255,983)
Contributions of investments	(9,599)	(8,755)
Change in operating lease measurement	1,717	-
(Increase) decrease in:		
Promises to give	103,000	(81,959)
Prepaid expenses	13,783	(24,087)
Inventories	71	285
Employee retention tax credit receivable	-	(64,721)
Increase (decrease) in:		
Accrued liabilities	(20,060)	4,369
Deferred revenues	-	(3,686)
Net cash provided by operating activities	<u>93,106</u>	<u>122,538</u>
Cash flow from investing activities:		
Purchases of fixed assets	-	(1,529)
Sales (purchases) of investments, net	(19,186)	(188,813)
Net cash used by investing activities	<u>(19,186)</u>	<u>(190,342)</u>
Net increase (decrease) in cash and equivalents	73,920	(67,804)
Cash and equivalents, beginning of year	626,437	694,241
Cash and equivalents, end of year	<u>\$ 700,357</u>	<u>\$ 626,437</u>
Cash paid for amounts included in lease measurement		
Operating cash flows from operating lease	56,925	-
Noncash Financing Transactions		
Right-of-use asset in exchange for operating lease liability	209,774	-

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 year ended December 31, 2022:

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, 2022, the Foundation adopted Accounting Standards Update (ASU) 2019-01 (Topic 842), which changed the accounting treatment for operating leases by requiring recognition of a lease asset and lease liability at present value of the lease payments in the Statement of Financial Position and disclosure of key information about leasing arrangements. The Foundation applied the new standard using the modified retrospective approach and adopted the practical expedient package to not reassess at adoption (i) expired or existing contracts for whether they are or contain a lease, (ii) the lease classification of an existing lease or (iii) initial indirect costs for existing leases.

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, 2022 was \$6,203.

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.

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 November 29, 2023, 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, 2022, the net assets of the Foundation totaled \$2,879,796. 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, 2022 was \$2,116,837.

Net assets with donor restrictions are available for the following purposes as of December 31, 2022:

21st Century Future Conferences Fund	\$ 2,006
2023 National Conference	19,044
Research Expenses	58,109
Special Events	293
Time Restrictions	100,211

Net assets released from restrictions for the years ended December 31 2022:

Satisfaction of program restrictions	\$ 10,300
Expiration of time restrictions	<u>75,000</u>
Total net assets released from restrictions	\$ 85,300

3. CONTRIBUTED SERVICES AND ASSETS

During the year ended December 31, 2022, 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 \$9,599 during the year ended December 31, 2022.

4. UNCONDITIONAL PROMISES TO GIVE

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

Due in less than one year	\$ -
Due in one to five years	<u>100,213</u>
	100,213
Less discount to present value	<u>1,254</u>
Total	\$ 98,959

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, 2022 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>Cost</u>	<u>Fair Value</u>
Mutual Funds	\$1,828,116	\$2,031,698

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

5. INVESTMENTS (continued)

Investment income for the year ended December 31, 2022 is as follows:

Interest and dividend income	\$ 47,337
Net realized gains	7,288
Net unrealized losses	(436,570)
Investment expenses	<u>(14,422)</u>
Total return	\$ (396,367)

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	\$ 1,792,044	\$ 2,432,196	\$ 640,152
Balance at end of year	\$ <u>1,828,116</u>	\$ <u>2,031,698</u>	<u>203,582</u>
Unrealized gains (losses) for the year			\$ <u>(436,570)</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>2022</u> \$ 2,895,735
Less those unavailable for general expenditures within one year, due to:	
Promise to give	98,959
Subject to donor-imposed restrictions:	80,704
Board designations:	
Amounts set aside for liquidity reserve	<u>2,116,837</u>
Financial assets available to meet cash needs for general expenditures within one year	\$ 599,235

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 when 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 \$10,082 for the year ended December 31, 2022.

8. FACILITY LEASE

On September 1, 2019, the Foundation entered into a lease agreement which expires on August 31, 2025. The lease contains a provision for one rent free month each year. Rent expense amounted to \$60,321 for the year ended December 31, 2022.

ASU 2019-01, Leases (Topic 842), changes the accounting treatment for operating leases by requiring the Foundation to assess whether an arrangement qualifies as a lease (i.e., conveys the right to control the use of an identified asset for a period of time in exchange for consideration) and to recognize a lease asset and lease liability at present value of the lease payments in the Statement of Financial Position as well as disclosure of key information about the leasing arrangement. The Foundation elected the practical expedient that allows leasees to choose to not separate lease and non-lease components by class of underlying asset and are applying this expedient to all relevant asset classes. The Foundation adopted the package of practical expedients to not perform any lease reclassification and did not reassess initial direct costs. As a result, the Foundation recorded a right-of-use asset and operating lease liability in the amount of \$209,774 by calculating the present value using a discount rate of 1.37%

The following is a schedule of the future minimum lease payments:

<u>Year Ending December 31,</u>	
2023	\$ 57,313
2024	58,348
2025	<u>42,435</u>
	158,096
Less: Discount to present value	<u>(2,794)</u>
	155,302
Less: Current portion	<u>(55,612)</u>
Long-term portion	\$ <u>99,690</u>

See independent auditor's report

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 2019.

10. 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 which was received on July 6, 2023.