Cornelia de Lange Syndrome Foundation, Inc.

FINANCIAL STATEMENTS

For the years ended December 31, 2024 and 2023

#### Cornelia de Lange Syndrome Foundation, Inc. Financial Statements For the years ended December 31, 2024 and 2023

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### BOTTARO, MORRILL & COMPANY, LLC

Certified Public Accountants

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#### Independent Auditor's Report

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 statements of financial position as of December 31, 2024 and 2023, and the related statements of activities, functional expenses and cash flows for the years 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, 2024 and 2023, 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.

#### 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.

Bottaro, Morrill & Company, LLC

September 18, 2025

# Cornelia de Lange Syndrome Foundation, Inc. Statements of Financial Position December 31, 2024 and 2023

		2024		2023
Assets				
Current assets:				
Cash and cash equivalents	\$	572 <b>,</b> 962	\$	585,100
Investments		2,602,105		2,386,032
Promises to give		125,000		70,000
Prepaid expenses		10,927		21,258
Fundraising inventory		3,793		2,507
Total current assets		3,314,787		3,064,897
Fixed assets:				
Equipment		73,320		73,320
Less: accumulated depreciation		(70,070)		(66,321)
Total fixed assets, net		3,250		6,999
Other assets:				
Promises to give - long term,				
net discount \$1,253 in 2023		_		98 <b>,</b> 959
Right-of-use asset, net		38,926		96,644
Total other assets		38,926		195,603
Total assets	\$	3,356,963	\$	3,267,499
Liabilities and Net Ass	sets			
Current liabilities:				
Accounts payable and accrued expenses	\$	46,257	\$	64 <b>,</b> 075
Lease liability		42,266		57 <b>,</b> 424
Total current liabilities		88,523		121,499
Lease liability - long-term				42,266
Net assets:				
Without donor restrictions:				
Undesignated funds		347,058		398,085
Board designated operating reserve		2,733,434		2,459,096
Total funds without donor restrictions		3,080,492		2,857,181
Net assets with donor restrictions		187,948		246,553
Total net assets		3,268,440	_	3,103,734
Total liabilities and net assets	\$	3,356,963	\$	3,267,499

### Cornelia de Lange Syndrome Foundation, Inc. Statements of Activities

For the years ended December 31, 2024 and 2023

	 2024		2023
Changes in net assets without donor restrictions:			
Support and revenues			
Contributions and donations	\$ 419,505	\$	454,676
Fundraising and special events	434,518		336,854
Grants	35 <b>,</b> 626		55,391
National conference	40,895		_
Interest and dividend income, net of fees	59,431		49,050
Net realized and unrealized gains (losses)	205,834		289,163
Net assets released from restrictions	 191,762		5,292
Total support and revenues	 1,387,571	_	1,190,426
Expenses:			
Program Services			
Family support	440,507		338,936
Public information and education	220,780		208,804
Professional development, outreach and			
awareness	179,924		196,173
Research	4,816		12,907
Total program services	 846,027		756,820
Management and general	145,633		131,893
Fundraising costs	122,883		102,039
Special events costs	49,717		42,626
Total expenses	1,164,260		1,033,378
Changes in net assets without donor restrictions	 223,311		157,048
Changes in net assets with donor restrictions:			
Contributions and grants	133,157		72 <b>,</b> 182
Net assets released from restrictions	 (191,762)		(5,292)
Changes in net assets with donor restrictions	 (58,605)		66,890
Total change in net assets	\$ 164,706	\$	223,938
Net assets, beginning of year	 3,103,734		2,879,796
Net assets, end of year	\$ 3,268,440	\$	3,103,734

## CORNELIA DE LANGE SYNDROME FOUNDATION, INC. Statements of Functional Expenses For the years ended December 31, 2024 and 2023

#### Program Services

		mily Program		nformation ucation	Development	ssional t, Outreach areness	Res	earch	Comparati	ve Totals
	2024	2023	2024	2023	2024	2023	2024	2023	2024	2023
Salaries, Payroll Taxes Employee Benefits	\$ 275,005	\$ 262,137	\$ 170,949	\$ 155,047	\$ 156,084	\$ 167,933		\$ -	\$ 602,038	\$ 585,117
Depreciation	1,427	1,923	721	1,138	581	1,232		-	\$ 2,729	\$ 4,293
Insurance	2,598	2,809	1,615	1,661	1,474	1,800		-	5,687	\$ 6,270
Meetings and Seminars	119,242	15,887		-		-		12,090	119,242	\$ 27,977
Office Expense	1,635	1,100	7,685	4,297		-		-	9,320	\$ 5,397
Postage	1,342	2,054	7,961	9,705		-		-	9,303	\$ 11,759
Professional Fees	4,689	18,303	2,363	2,504	2,210	2,239	4,816	-	14,078	\$ 23,046
Rent	22,140	22,315	13,581	13,199	12,400	14,324		-	48,121	\$ 49,838
Printing	302	1,186	8,350	14,481		-		817	8,652	\$ 16,484
Telephone	2,691	2,450	1,673	1,449	1,527	1,569		-	5,891	\$ 5,468
Dues and Subscriptions	5,100	3,993	3,187	2,496	3,187	4,014		-	11,474	\$ 10,503
Equipment Rental and Maintenance	4,336	4,779	2,695	2,827	2,461	3,062			9,492	\$ 10,668
Total Expenses	\$ 440,507	\$ 338,936	\$ 220,780	\$ 208,804	\$ 179,924	\$ 196,173	\$4,816	\$12 <b>,</b> 907	\$ 846,027	\$ 756,820

## CORNELIA DE LANGE SYNDROME FOUNDATION, INC. Statements of Functional Expenses For the years ended December 31, 2024 and 2023

#### Support Services

	Management and General Fund Raising Co					
	2024	2023	2024	2023	2024	2023
Salaries, Payroll Taxes Employee Benefits	\$ 59,461	\$ 42 <b>,</b> 857	\$ 81,758	\$ 67,393	\$ 141,219	\$ 110,250
Depreciation	465	314	555	494	\$ 1,020	\$ 808
Insurance	562	459	772	722	\$ 1,334	\$ 1,181
Meetings and Seminars	12,145	12,875	7,538	4,884	\$ 19,683	\$ 17,759
Office Expense	3,083	3,868	3,257	2,392	\$ 6,340	\$ 6,260
Postage	2,406	2,317	3,306	4,398	\$ 5,712	\$ 6,715
Professional Fees	58,386	63,413	10,003	6,567	\$ 68,389	\$ 69,980
Rent	4,724	3,611	6,495	5,741	\$ 11,219	\$ 9,352
Printing	145	-	7,110	4,650	\$ 7,255	\$ 4,650
Telephone	582	400	800	630	\$ 1,382	\$ 1,030
Dues and Subscriptions  Equipment Rental and	1,275	998		2,939	\$ 1,275	\$ 3,937
Maintenance	2,399	781	1,289	1,229	\$ 3,688	\$ 2,010
Total Expenses	\$ 145,633	\$ 131,893	\$ 122,883	\$ 102 <b>,</b> 039	\$ 268,516	\$ 233 <b>,</b> 932

# Cornelia de Lange Syndrome Foundation, Inc. Statements of Cash Flows For the years ended December 31, 2024 and 2023

	 2024	 2023
Cash flows from operating activities:		
Change in net assets	\$ 164,706	\$ 223,938
Adjustments to reconcile change in net assets to		
net cash provided by operating activities:		
Depreciation and amortization	3,749	5,102
Net realized and unrealized (gains) losses	(205,834)	(289,163)
Contributions of investments	(10, 239)	(9 <b>,</b> 701)
Change in operating lease measurement	294	1,329
(Increase) decrease in:		
Promises to give	43,959	(70,000)
Prepaid expenses	10,331	(3,094)
Inventories	(1,286)	_
Employee retention tax credit receivable	_	64 <b>,</b> 721
<pre>Increase (decrease) in:</pre>		
Accrued liabilities	(17,818)	17,862
Deferred revenues	_	(782)
Net cash used by operating activities	(12,138)	(59,788)
Cash flow from investing activities:		
Sales (purchases) of investments, net		 (55,469)
Net cash used by investing activities	_	(55,469)
Net decrease in cash and equivalents	(12,138)	(115,257)
Cash and equivalents, beginning of year	 585,100	 700,357
Cash and equivalents, end of year	\$ 572,962	\$ 585,100
Cash paid for amounts included in lease measurement		
Operating cash flows from operating lease	58,348	57,861

#### 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, 2024 and 2023:

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)

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, 2024 and 2023 was \$3,749 and \$5,101 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.

#### 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 September 18, 2025, 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, 2024 and 2023, the net assets of the Foundation totaled \$3,268,440 and \$3,103,734, 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, 2024 and 2023 was \$2,733,434 and \$2,459,096, respectively.

Net assets with donor restrictions are available for the following purposes as of December 31, 2024 and 2023:

	<u> 2024</u>	<u> 2023 </u>
Research Expenses	\$ 54 <b>,</b> 997	\$ 54 <b>,</b> 792
Printing Costs	6,000	_
Special Events	1,951	_
Time Restrictions	125,000	_
21st Century Future Conferences Fund	_	2,006
2024 National Conference	_	19,544

Net assets released from restrictions for the years ended December  $31\ 2024$  and 2023:

	2024	2023
Satisfaction of program restrictions	\$ 21,550	\$ 5,292
Expiration of time restrictions	170,212	
Total net assets released from restrictions	\$ 191,762	\$ 5,292

#### 3. CONTRIBUTED SERVICES AND ASSETS

During the years ended December 31, 2024 and 2023, 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 \$10,238 and \$9,701 during the years ended December 31, 2024 and 2023 respectively.

#### 4. UNCONDITIONAL PROMISES TO GIVE

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

	0004	0.000
	<u> 2024                                   </u>	<u> 2023                                   </u>
Due in less than one year	\$ 125,000	\$ 70,000
Due in one to five years		100,213
	125,000	170,213
Less discount to present value		<u> 1,254</u>
Total	\$ 125 <b>,</b> 000	\$ 168,959

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, 2023 was 1.25%. Amortization of the discount is reported in the Statements 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. Investments are stated at fair value and consist of the following at December 31:

	2024	2023
Equities	\$ -	\$ 24,752
Mutual funds	1,099,676	1,077,670
Exchanged traded funds	1,502,429	<u>1,283,610</u>
	\$2,602,105	\$2,386,032

#### 5. INVESTMENTS (continued)

Investment income for the years ended December 31, 2024 and 2023 is as follows:

	2024	2023
Interest and dividend income	\$ 76 <b>,</b> 333	\$ 63 <b>,</b> 517
Net realized gains	12,552	17 <b>,</b> 772
Net unrealized gains (losses)	193,282	271,391
Investment expenses	( <u>16,902</u> )	( <u>14,467</u> )
Total return	\$ 265,265	\$ 338,213

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

		Fair	Excess of Fair Value
Balance at beginning of year Balance at end of year	Cost \$ 1,902,417 \$ 1,925,208	Value \$ 2,386,032 \$ 2,602,105	<u>Over Cost</u> \$ 483,615 <u>676,897</u>
Unrealized gains (losses) for the year			\$ <u>193,282</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	\$ 2024 3,300,067
Less those unavailable for general expenditures within one year, due to:	
Promise to give	125,000
Subject to donor-imposed restrictions:	62,948
Board designations:  Amounts set aside for liquidity reserve	2,733,434
Financial assets available to meet cash needs for general expenditures within one year	\$ 378 <b>,</b> 685

#### 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 \$8,543 and \$8,495 for the years ended December 31, 2024 and 2023 respectively.

#### 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.

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 Statements of Financial Position as well as disclosure of key information about the leasing arrangement. As a result, the Foundation recorded a right-of-use asset and operating lease liability in the amount of \$209,774 in 2024 by calculating the present value using a discount rate of 1.37%. The lease contains variable payments based on a percentage of costs over contractual levels, which are not determinable at the lease commencement and are not included in the measurement of lease assets and liabilities. Operating lease costs for the years ended December 31, 2024 and 2023 were \$59,340 and \$59,190, respectively, with a weighted-average remaining lease term of .67 years and 1.67 years, respectively.

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

Year Ending December 31,	
2025	\$ 42,435
Less: Discount to present value	( 169)
Current portion	\$ 42,266

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

#### 8. FACILITY LEASE (continued)

Subsequent to the date of these financial statements, the Foundation signed a lease extension, with a commencement date of October 2025 and expiring on August 31, 2030, for an annual rent of \$45,672 subject to three percent annual increases every subsequent anniversary of the commencement date.

#### 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 2021.

#### 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.