

Cornelia de Lange  
Syndrome Foundation, Inc.

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FINANCIAL STATEMENTS

For the years ended  
December 31, 2015 and 2014

Cornelia de Lange Syndrome Foundation, Inc.  
Financial Statements  
For the years ended December 31, 2015 and 2014

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# BOTTARO, MORRILL & COMPANY, LLC

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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, 2015 and 2014, 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, 2015 and 2014, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.



Bottaro, Morrill & Company, LLC

October 25, 2016

Cornelia de Lange Syndrome Foundation, Inc.  
 Statements of Financial Position  
 December 31, 2015 and 2014

	2015	2014
<b>Assets</b>		
Current assets:		
Cash and cash equivalents	\$ 610,553	\$ 457,483
Promises to give	-	100,100
Investments	658,873	667,033
Fundraising inventory	5,464	-
Total current assets	1,274,890	1,224,616
Fixed assets:		
Equipment	66,934	66,934
Less: accumulated depreciation	(60,379)	(55,550)
Total fixed assets, net	6,555	11,384
Other asset:		
Security deposit	1,230	1,230
Total assets	\$ 1,282,675	\$ 1,237,230

**Liabilities and Net Assets**

Current liabilities:		
Accounts payable and accrued expenses	\$ 23,533	\$ 40,604
Net assets:		
General funds	423,717	324,937
Board designated funds	747,669	684,983
Total unrestricted funds	1,171,386	1,009,920
Temporarily restricted net assets	87,756	186,706
Total net assets	1,259,142	1,196,626
Total liabilities and net assets	\$ 1,282,675	\$ 1,237,230

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, 2015 and 2014

	2015	2014
Unrestricted Net Assets:		
Support		
Contributions and donations	\$ 395,903	\$ 392,437
Special events	427,525	446,132
Grants	55,069	72,147
Fundraising merchandise sales, net of costs	1,431	-
National conference	-	61,210
Net assets released from restrictions	100,100	100,338
Total support revenue	980,028	1,072,264
Revenue		
Interest and dividend income, net of fees	11,572	12,499
Net realized and unrealized gains (losses)	(33,524)	16,910
Total revenue	(21,952)	29,409
Total support and revenue	958,076	1,101,673
Expenses:		
Program Services (Schedule I)		
Family support	276,828	383,788
Public information and education	196,053	281,405
Professional development, outreach and awareness	176,679	180,938
Research	44,057	43,517
Total program services	693,617	889,648
Support Services (Schedule II)		
Management and general	43,568	51,230
Fundraising costs	59,425	72,818
Total support services	102,993	124,048
Total expenses	796,610	1,013,696
Change in unrestricted net assets	161,466	87,977
Temporarily Restricted Net Assets:		
Contributions and grants	1,150	167,428
Net assets released from restrictions	(100,100)	(100,338)
Change in temporarily restricted net assets	(98,950)	67,090
Total change in net assets	\$ 62,516	\$ 155,067
Net assets, beginning of year	1,196,626	1,041,559
Net assets, end of year	\$ 1,259,142	\$ 1,196,626

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, 2015 and 2014

	Program Services									
	Family Support Program		Public Information and Education		Professional Development, Outreach and Awareness		Research		Comparative Totals	
	2015	2014	2015	2014	2015	2014	2015	2014	2015	2014
Salaries, Payroll Taxes Employee Benefits	\$ 178,048	\$ 181,036	\$ 108,678	\$ 105,113	\$ 129,489	\$ 127,350	\$ 4,625	\$ 4,228	\$ 420,840	\$ 417,727
Depreciation	-	-	-	-	-	-	-	-	-	-
Events and Public Relations	21,955	28,765	20,540	22,463	10,910	14,116	1,125	705	54,530	66,049
Insurance	1,690	1,635	1,268	1,154	1,054	999	1,364	1,288	5,376	5,076
Meetings and Seminars	17,047	104,153	9,529	88,135	2,387	8,548	1,416	2,393	30,379	203,229
Office Expense	1,458	4,931	2,293	5,977	1,320	4,100	320	125	5,391	15,133
Postage	5,272	8,223	9,778	4,913	804	4,625	48	-	15,902	17,761
Professional Fees	17,467	21,580	15,064	19,856	11,468	6,667	-	-	43,999	48,103
Rent	15,289	15,289	9,513	9,513	6,795	6,795	340	340	31,937	31,937
Printing	7,909	6,345	9,514	11,722	6,041	2,005	-	-	23,464	20,072
Telephone	2,019	1,775	1,250	1,281	520	388	54	65	3,843	3,509
Research Grants	-	-	-	-	-	-	34,765	33,750	34,765	33,750
Dues and Subscriptions	5,782	4,096	5,371	4,773	2,133	1,245	-	-	13,286	10,114
Equipment Rental and Maintenance	2,892	5,960	3,255	6,505	3,758	4,100	-	623	9,905	17,188
<b>Total Expenses</b>	<b>\$ 276,828</b>	<b>\$ 383,788</b>	<b>\$ 196,053</b>	<b>\$ 281,405</b>	<b>\$ 176,679</b>	<b>\$ 180,938</b>	<b>\$ 44,057</b>	<b>\$ 43,517</b>	<b>\$ 693,617</b>	<b>\$ 889,648</b>

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, 2015 and 2014

	Support Services					
	Management and General		Fund Raising		Comparative Totals	
	2015	2014	2015	2014	2015	2014
Salaries, Payroll Taxes Employee Benefits	\$ 16,186	\$ 16,549	\$ 25,435	\$ 38,545	\$ 41,621	\$ 55,094
Depreciation	4,829	7,380	-	-	4,829	7,380
Events and Public Relations	954	2,120	10,978	9,150	11,932	11,270
Insurance	179	170	237	224	416	394
Meetings and Seminars	1,727	2,155	5,092	4,174	6,819	6,329
Office Expense	2,502	4,524	960	1,039	3,462	5,563
Postage	1,204	1,175	2,504	3,003	3,708	4,178
Professional Fees	8,639	9,285	1,211	1,798	9,850	11,083
Rent	1,019	1,019	1,019	1,019	2,038	2,038
Printing	1,162	902	5,348	5,238	6,510	6,140
Telephone	110	125	85	125	195	250
Research Grants	-	-	-	-	-	-
Dues and Subscriptions	1,756	2,141	1,788	1,652	3,544	3,793
Equipment Rental and Maintenance	3,301	3,685	4,768	6,851	8,069	10,536
Total Expenses	\$ 43,568	\$ 51,230	\$ 59,425	\$ 72,818	\$ 102,993	\$ 124,048

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, 2015 and 2014

	2015	2014
Cash flows from operating activities:		
Change in net assets	\$ 62,516	\$ 155,067
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	4,829	7,380
Net realized and unrealized (gains) losses	33,524	(16,910)
Contributions of investments	(10,130)	(15,921)
(Increase) decrease in:		
Promises to give	100,100	(100,100)
Inventories	(5,464)	-
Increase (decrease) in:		
Accrued liabilities	(17,071)	24,525
Deferred revenues	-	(750)
Net cash provided by operating activities	168,304	53,291
Cash flow from investing activities:		
Purchases of fixed assets	-	(2,520)
Net purchases of investments	(15,234)	(30,589)
Net cash used by investing activities	(15,234)	(33,109)
Net increase in cash and equivalents	153,070	20,182
Cash and equivalents, beginning of year	457,483	437,301
Cash and equivalents, end of year	\$ 610,553	\$ 457,483

See independent auditor's report and notes to financial statements



1. **SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES**

**Description of Foundation** - Cornelia de Lange Syndrome Foundation, Inc. (the Foundation) was incorporated in December 1981 as a family support organization, which exists to ensure early and accurate diagnosis of Cornelia de Lange Syndrome (CdLS), promote research into the causes and manifestations of the syndrome, and assist with a diagnosis of CdLS. From its sole office in Avon, Connecticut, Foundation Family Service Coordinators (FSCs) respond to the needs of families and health professionals by providing information about the syndrome, facilitating access to the Foundation's Clinical Advisory Board, and maintaining a national network of volunteer coordinators who extend the support services available. In addition, the Foundation operates numerous programs and produces publications to promote awareness of the syndrome and its impact on families.

The Foundation has the following programs for the years ended December 31, 2015 and 2014:

**Family Support** - Family Service Coordinators (FSCs) address needs of family members and health professionals in both the short and long term. FSCs answer phone calls from parents whose children have been recently diagnosed, parents needing guidance for a medical or educational decision, or families whose child has recently become ill or passed away. FSCs focus the resources of the Foundation on families by coordinating regional gatherings, supporting volunteer regional coordinators and serving as the direct point-of-contact for all family calls to the office.

**Public Information and Education** - The Foundation produces numerous educational publications, including a quarterly newsletter, Reaching Out, to communicate valuable information to families, friends, and health professionals nationwide.

**Professional Development, Outreach and Awareness** - In-house public affairs staff work to promote awareness of CdLS and the services available to professionals through the Foundation. Awareness efforts are achieved with the assistance of a nationwide network of volunteer awareness coordinators who host events, encourage media coverage of families caring for children with CdLS, and distribute Foundation-related promotional items to their local health professional community as well as to their community at-large.

**Research** - The Foundation supports basic science and clinical research projects to ensure that the information it provides remains the most current and accurate available.

**Basis of Accounting** - The financial statements of the Foundation have been prepared on the accrual basis. The significant accounting policies followed are described below to enhance the usefulness of the financial statements to the reader.

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

**Financial Statement Presentation** - Net assets, support and revenues, and expenses, are classified as unrestricted and temporarily restricted based upon the following criteria:

- Unrestricted net assets represent expendable funds available for operations, which are not otherwise limited by donor restrictions. Included in unrestricted net assets are Board-designated funds which are not donor restricted and do not meet the definition of restricted net assets.
- Temporarily 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, 2015 and 2014 was \$4,829 and \$7,380, 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.

**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.

See independent auditor's report

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

**2. NET ASSETS**

The net assets of the Foundation are considered unrestricted and temporarily restricted as defined by generally accepted accounting principles (See Note 1). At December 31, 2015 and 2014 the net assets of the Foundation totaled \$1,259,142 and \$1,196,626, 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.

Temporarily restricted net assets are available for the following purposes:

	2015	2014
Time restrictions	\$ -0-	\$ 100,100
21st Century Future Conferences Fund	87,756	86,606

**3. CONTRIBUTED SERVICES AND ASSETS**

During the years ended December 31, 2015 and 2014, 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 assets and stock valued at \$10,130 and \$15,921 during the years ended December 31, 2015 and 2014, respectively.

**4. INVESTMENTS**

The Foundation investments are carried at fair value based on quoted prices in active markets (all Level 1 measurements). Accordingly, the gains or losses that result from changes in fair value are reported in the statement of activities for the period in which they occur.

	2015		2014	
	Cost	Fair Value	Cost	Fair Value
Mutual Funds	\$595,111	\$658,873	\$574,814	\$667,033

Investment income for the years ended December 31, 2015 and 2014 is as follows:

	2015	2014
Interest and Dividend Income	\$ 18,820	\$ 18,974
Net realized gains (losses)	(5,067)	2,312
Net unrealized gains (losses)	(28,457)	14,598
Investment expenses	(7,248)	(6,475)
Total return	\$ (21,952)	\$ 29,409

See independent auditor's report

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

4. **INVESTMENTS (continued)**

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

	<u>Carrying Value</u>	<u>Fair Value</u>	<u>Excess of Fair Value Over Cost</u>
Balance at beginning of year	\$574,814	\$667,033	\$ 92,219
Balance at end of year	<u>595,111</u>	<u>658,873</u>	<u>63,762</u>
Unrealized gains (losses) for the year			\$ <u>(28,457)</u>

5. **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. The Foundation does not match employee contributions.

6. **FACILITY LEASE**

On April 1, 2014, the Foundation extended the terms of the current lease agreement through February 2018 at an annual rent of \$33,975. Rent expense amounted to \$33,975 for the years ended December 31, 2015 and 2014.

The following is a schedule of future minimum rental payments required under the above operating lease as of December 31, 2015.

<u>Year Ending December 31,</u>	<u>Amount</u>
2016	\$ 33,975
2017	33,975
2018	5,663

7. **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 2012.

8. **EVALUATION OF SUBSEQUENT EVENTS**

The Organization has evaluated subsequent events through October 25, 2016, the date which the financial statements were available to be issued.

See independent auditor's report