Cornelia de Lange Syndrome Foundation, Inc.

FINANCIAL STATEMENTS

For the years ended December 31, 2014 and 2013

Cornelia de Lange Syndrome Foundation, Inc. Financial Statements For the years ended December 31, 2014 and 2013

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BOTTARO, MORRILL & COMPANY, LLC

Certified Public Accountants

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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, 2014 and 2013, 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, 2014 and 2013, 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

July 29, 2015

Cornelia de Lange Syndrome Foundation, Inc. Statements of Financial Position December 31, 2014 and 2013

| | | 2014 | | 2013 |
|---------------------------------------|------|-----------|----|-----------|
| Assets | | | | _ |
| Current assets: | | | | |
| Cash and cash equivalents | \$ | 457,483 | \$ | 437,301 |
| Promises to give | | 100,100 | | - |
| Investments | | 667,033 | | 603,612 |
| Total current assets | _ | 1,224,616 | _ | 1,040,913 |
| Fixed assets: | | | | |
| Equipment | | 66,934 | | 64,414 |
| Less: accumulated depreciation | | (55,550) | | (48,170) |
| Total fixed assets, net | _ | 11,384 | | 16,244 |
| Other asset: | | | | |
| Security deposit | | 1,230 | | 1,230 |
| Total assets | \$ | 1,237,230 | \$ | 1,058,387 |
| Liabilities and Net Ass | sets | | | |
| Current liabilities: | | | | |
| Accounts payable and accrued expenses | \$ | 40,604 | \$ | 16,078 |
| Deferred revenue | | | | 750 |
| | | 40,604 | | 16,828 |
| Net assets: | | | | |
| General funds | | 324,937 | | 306,960 |
| Board designated funds | | 684,983 | | 614,983 |
| Total unrestricted funds | | 1,009,920 | | 921,943 |
| Temporarily restricted net assets | | 186,706 | | 119,616 |
| Total net assets | | 1,196,626 | | 1,041,559 |
| Total liabilities and net assets | \$ | 1,237,230 | \$ | 1,058,387 |

Cornelia de Lange Syndrome Foundation, Inc. Statements of Activities For the years ended December 31, 2014 and 2013

| | 2014 | 2013 |
|---|--------------|--------------|
| Unrestricted Net Assets: | | |
| Support | | |
| Contributions and donations | \$ 392,437 | \$ 391,251 |
| Special events | 446,132 | 418,140 |
| Grants | 72,147 | 54,693 |
| National conference | 61,210 | - |
| Net assets released from restrictions | 100,338 | |
| Total support revenue | 1,072,264 | 864,084 |
| Revenue | | |
| Interest and dividend income, net of fees | 12,499 | 10,273 |
| Net realized and unrealized gains (losses) | 16,910 | 57,896 |
| Total revenue | 29,409 | 68,169 |
| Total support and revenue | 1,101,673 | 932,253 |
| Expenses: | | |
| Program Services (Schedule I) | | |
| Family support | 383,788 | 285,358 |
| Public information and education | 281,405 | 186,431 |
| Professional development, outreach and | | |
| awareness | 180,938 | 203,539 |
| Research | 43,517 | 35,479 |
| Total program services | 889,648 | 710,807 |
| Support Services (Schedule II) | | |
| Management and general | 51,230 | 50,901 |
| Fundraising costs | 72,818 | 69,406 |
| Total support services | 124,048 | 120,307 |
| Total expenses | 1,013,696 | 831,114 |
| Change in unrestricted net assets | 87,977 | 101,139 |
| Temporarily Restricted Net Assets: | | |
| Contributions and grants | 167,428 | 73,010 |
| Net assets released from restrictions | (100,338) | |
| Change in temporarily restricted net assets | 67,090 | 73,010 |
| Total change in net assets | \$ 155,067 | \$ 174,149 |
| Net assets, beginning of year | 1,041,559 | 867,410 |
| Net assets, end of year | \$ 1,196,626 | \$ 1,041,559 |

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, 2014 and 2013

| | | | | | Program | Services | | | | |
|--|--|---------|--|--------------------|---|-----------|------|---------------------------|-----|----------------------------|
| | Family Support Program | ogram | Public Information and Education | Pro Dev Out: | Professional Development, Outreach and Awareness | Research | Prog | Total Program Services | Com | Comparative Totals 2013 |
| Salaries, Payroll Taxes Employee Benefits | \$ 181 | 181,036 | \$ 105,113 | w | 127,350 | \$ 4,228 | ‹ | 417,727 | ᡐ | 418,732 |
| Depreciation | | · | | | ŧ | , | | • | | 1 |
| Events and Public Relations | 28 | 28,765 | 22,463 | | 14,116 | 705 | | 66,049 | | 69,793 |
| Insurance | П | 1,635 | 1,154 | | 666 | 1,288 | | 5,076 | | 4,830 |
| Meetings and Seminars | 104 | 104,153 | 88,135 | | 8,548 | 2,393 | | 203,229 | | 43,559 |
| Office Expense | 4 | 4,931 | 5,977 | | 4,100 | 125 | | 15,133 | | 5,471 |
| Postage | æ | 8,223 | 4,913 | | 4,625 | 1 | | 17,761 | | 17,871 |
| Professional Fees | 21 | 21,580 | 19,856 | | 6,667 | ' | | 48,103 | | 41,172 |
| Rent | 1.5 1.5 1.5 1.5 1.5 1.5 1.5 1.5 1.5 1.5 | 15,289 | 9,513 | | 6,795 | 340 | | 31,937 | | 31,937 |
| Printing | 9 | 6,345 | 11,722 | | 2,005 | 1 | | 20,072 | | 26,170 |
| Telephone | rd | 1,775 | 1,281 | | 388 | 65 | | 3,509 | | 3,784 |
| Research Grants | | ı | 1 | | ı | 33,750 | | 33,750 | | 20,000 |
| Dues and Subscriptions | 4 | 4,096 | 4,773 | | 1,245 | 1 | | 10,114 | | 11,337 |
| Equipment Rental and Maintenance | 3, | , 960 | 6,505 | | 4,100 | 623 | | 17,188 | | 16,151 |
| Total Expenses | \$ 383 | , 788 | \$ 281,405 | v. | 180,938 | \$ 43,517 | v- | 889,648 | w | 710,807 |

CORNELIA DE LANGE SYNDROME FOUNDATION, INC. Statements of Functional Expenses For the years ended December 31, 2014 and 2013

| | | | | Support Services | Services | | | |
|--|-----------------------|----------------|------|------------------|------------|------------------------------|-------|----------------------------|
| | Management General | ent and ral | Fund | Fund Raising | Sup Ser | Total Support Services | Compa | Comparative Totals 2013 |
| Salaries, Payroll Taxes Employee Benefits | ত | 16,549 | w | 38,545 | ¢\$ | 55,094 | ₩ | 52,298 |
| Depreciation | | 7,380 | | i | | 7,380 | | 13,002 |
| Events and Public Relations | | 2,120 | | 9,150 | | 11,270 | | 6,903 |
| Insurance | | 170 | | 224 | | 394 | | 374 |
| Meetings and Seminars | | 2,155 | | 4,174 | | 6,329 | | 5,928 |
| Office Expense | | 4,524 | | 1,039 | | 5,563 | | 5,123 |
| Postage | | 1,175 | | 3,003 | | 4,178 | | 4,759 |
| Professional Fees | | 9,285 | | 1,798 | | 11,083 | | 5,934 |
| Rent | | 1,019 | | 1,019 | | 2,038 | | 2,038 |
| Printing | | 902 | | 5,238 | | 6,140 | | 4,330 |
| Telephone | | 125 | | 125 | | 250 | | 115 |
| Research Grants | | ſ | | ı | | ı | | • |
| Dues and Subscriptions | | 2,141 | | 1,652 | | 3,793 | | 2,216 |
| Equipment Rental and Maintenance | : | 3,685 | | 6,851 | | 10,536 | | 17,287 |
| Total Expenses | ഹ | 51,230 | ÷ | 72,818 | ూ | 124,048 | တ | 120,307 |

Cornelia de Lange Syndrome Foundation, Inc. Statements of Cash Flows For the years ended December 31, 2014 and 2013

| | 2014 | 2013 |
|---|---------------|---------------|
| Cash flows from operating activities: Change in net assets | \$ 155,067 | \$ 174,149 |
| Adjustments to reconcile change in net assets to net cash provided by operating activities: | | |
| Depreciation and amortization | 7,380 | 13,002 |
| Net realized and unrealized (gains) losses | (16,910) | (57,896) |
| Contributions of investments | (15,921) | (17,595) |
| (Increase) decrease in: | | |
| Promises to give | (100,100) | - |
| Increase (decrease) in: | | |
| Accounts payable | 24,525 | (3,150) |
| Deferred revenues | (750) | 750 |
| Net cash provided by operating activities | 53,291 | 109,260 |
| Cash flow from investing activities: | | |
| Purchases of fixed assets | (2,520) | (3,518) |
| Net purchases of investments | (30,589) | (19,735) |
| Net cash used by investing activities | (33,109) | (23,253) |
| Net increase in cash and equivalents | 20,182 | 86,007 |
| Cash and equivalents, beginning of year | 437,301 | 351,294 |
| Cash and equivalents, end of year | \$ 457,483 | \$ 437,301 |

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, 2014 and 2013:

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.

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 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 Boarddesignated 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, 2014 and 2013 was \$7,380 and \$13,002, respectively.

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.

Cornelia de Lange Syndrome 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, 2014 and 2013 the net assets of the Foundation totaled \$1,196,626 and \$1,041,559, 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:

| | 2014 | 2013 |
|--------------------------------------|------------|--------|
| Time restrictions | \$ 100,100 | \$ - |
| 21st Century Future Conferences Fund | 86,606 | 66,606 |
| 2014 National Conference | _ | 53.010 |

3. CONTRIBUTED SERVICES AND ASSETS

During the years ended December 31, 2014 and 2013, 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 \$15,921 and \$17,595 during the years ended December 31, 2014 and 2013, respectively.

4. INVESTMENTS

The Foundation maintains its investments at fair value. 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.

Investments at December 31, 2014 and 2013 are summarized as follows:

| | 2014 | 2013 |
|--------------|------------|---------|
| Mutual Funds | \$ 667,033 | 603,612 |

Investment return for the years ended December 31, 2014 and 2013 is as follows:

| | 2014_ | 2013 |
|--|-----------|-----------------|
| Interest and Dividend Income | \$ 18,974 | \$ 15,746 |
| Net realized & unrealized gains (losses) | 16,910 | 57,896 |
| Investment expenses | (6,475) | <u>(5,473</u>) |
| Total return | \$ 29,409 | \$ 68.169 |

4. INVESTMENTS (continued)

During the years ended December 31, 2014 and 2013, available-for-sale securities were sold for total proceeds of \$304,698 and \$221,411, respectively. The gross realized gains (losses) on these sales totaled \$35,071 and \$(2,425) in 2014 and 2013 respectively. For the purpose of determining gross realized gains (losses), the cost of securities sold is based on specific identification. Net unrealized holdings gains (losses) on available-for-sale securities in the amount of \$(18,161) and \$60,321 for the years ended December 31, 2014 and 2013 respectively, have been included in revenues.

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, 2014 and 2013.

The following is a schedule of future minimum rental payments required under the above operating lease as of December 31, 2014.

| Year Ending December 31, | Amount |
|--------------------------|-----------|
| 2015 | \$ 33,975 |
| 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 2011.

8. EVALUATION OF SUBSEQUENT EVENTS

The Organization has evaluated subsequent events through July 29, 2015, the date which the financial statements were available to be issued.