

Cornelia de Lange  
Syndrome Foundation, Inc.

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FINANCIAL STATEMENTS

For the years ended  
December 31, 2017 and 2016

Cornelia de Lange Syndrome Foundation, Inc.  
Financial Statements  
For the years ended December 31, 2017 and 2016

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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, 2017 and 2016, 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, 2017 and 2016, 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 2, 2018

Cornelia de Lange Syndrome Foundation, Inc.

Statements of Financial Position

December 31, 2017 and 2016

|                                | 2017                       | 2016                       |
|--------------------------------|----------------------------|----------------------------|
| <b>Assets</b>                  |                            |                            |
| Current assets:                |                            |                            |
| Cash and cash equivalents      | \$ 345,591                 | \$ 427,461                 |
| Investments                    | 812,399                    | 792,065                    |
| Promises to give               | 37,621                     | -                          |
| Prepaid expenses               | 11,607                     | -                          |
| Fundraising inventory          | 4,838                      | 5,177                      |
| Total current assets           | <u>1,212,056</u>           | <u>1,224,703</u>           |
| Fixed assets:                  |                            |                            |
| Equipment                      | 77,761                     | 72,284                     |
| Less: accumulated depreciation | (65,339)                   | (64,282)                   |
| Total fixed assets, net        | <u>12,422</u>              | <u>8,002</u>               |
| Other asset:                   |                            |                            |
| Security deposit               | <u>1,230</u>               | <u>1,230</u>               |
| Total assets                   | <u><u>\$ 1,225,708</u></u> | <u><u>\$ 1,233,935</u></u> |

Liabilities and Net Assets

|                                       |                            |                            |
|---------------------------------------|----------------------------|----------------------------|
| Current liabilities:                  |                            |                            |
| Accounts payable and accrued expenses | <u>\$ 22,526</u>           | <u>\$ 27,067</u>           |
| Net assets:                           |                            |                            |
| General funds                         | 244,932                    | 306,275                    |
| Board designated funds                | 820,951                    | 809,837                    |
| Total unrestricted funds              | <u>1,065,883</u>           | <u>1,116,112</u>           |
| Temporarily restricted net assets     | <u>137,299</u>             | <u>90,756</u>              |
| Total net assets                      | <u>1,203,182</u>           | <u>1,206,868</u>           |
| Total liabilities and net assets      | <u><u>\$ 1,225,708</u></u> | <u><u>\$ 1,233,935</u></u> |

See independent auditor's report and notes to financial statements



Cornelia de Lange Syndrome Foundation, Inc.  
 Statements of Activities  
 For the years ended December 31, 2017 and 2016

|  | <u>2017</u>         | <u>2016</u>         |
|--|---------------------|---------------------|
| Unrestricted Net Assets:                         |                     |                     |
| Support  |                     |                     |
| Contributions and donations                      | \$ 345,722          | \$ 388,451          |
| Special events                                   | 459,538             | 386,079             |
| Grants   | 51,066              | 51,785              |
| Fundraising merchandise sales, net of costs      | (6,676)             | (2,331)             |
| National conference                              | -                   | 140,903             |
| Net assets released from restrictions            | -                   | -                   |
| Total support revenue                            | <u>849,650</u>      | <u>964,887</u>      |
| Revenue  |                     |                     |
| Interest and dividend income, net of fees        | 7,099               | 7,302               |
| Net realized and unrealized gains                | 90,736              | 45,252              |
| Total revenue                                    | <u>97,835</u>       | <u>52,554</u>       |
| Total support and revenue                        | <u>947,485</u>      | <u>1,017,441</u>    |
| Expenses:  |                     |                     |
| Program Services (Schedule I)                    |                     |                     |
| Family support                                   | 329,663             | 457,217             |
| Public information and education                 | 228,867             | 212,443             |
| Professional development, outreach and awareness | 213,672             | 217,879             |
| Research   | 57,479              | 54,012              |
| Total program services                           | <u>829,681</u>      | <u>941,551</u>      |
| Support Services (Schedule II)                   |                     |                     |
| Management and general                           | 79,945              | 59,741              |
| Fundraising costs                                | 88,088              | 71,423              |
| Total support services                           | <u>168,033</u>      | <u>131,164</u>      |
| Total expenses                                   | <u>997,714</u>      | <u>1,072,715</u>    |
| Change in unrestricted net assets                | <u>(50,229)</u>     | <u>(55,274)</u>     |
| Temporarily Restricted Net Assets:               |                     |                     |
| Contributions and grants                         | 46,543              | 3,000               |
| Net assets released from restrictions            | -                   | -                   |
| Change in temporarily restricted net assets      | <u>46,543</u>       | <u>3,000</u>        |
| Total change in net assets                       | \$ (3,686)          | \$ (52,274)         |
| Net assets, beginning of year                    | <u>1,206,868</u>    | <u>1,259,142</u>    |
| Net assets, end of year                          | <u>\$ 1,203,182</u> | <u>\$ 1,206,868</u> |

See independent auditor's report and notes to financial statements

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.  
Statements of Functional Expenses  
For the years ended December 31, 2017 and 2016

**Program Services**

|  | Family Support Program |            | Public Information and Education |            | Professional Development, Outreach and Awareness |            | Research  |           | Comparative Totals |            |
|--|------------------------|------------|----------------------------------|------------|--|------------|-----------|-----------|--------------------|------------|
|  | 2017                   | 2016       | 2017                             | 2016       | 2017   | 2016       | 2017      | 2016      | 2017               | 2016       |
| Salaries, Payroll Taxes<br>Employee Benefits | \$ 222,610             | \$ 192,060 | \$ 135,879                       | \$ 117,231 | \$ 161,898                                       | \$ 139,680 | \$ 5,782  | \$ 4,989  | \$ 526,169         | \$ 453,960 |
| Depreciation                                 | -                      | -          | -                                | -          | -  | -          | -         | -         | -                  | -          |
| Events and Public Relations                  | 18,403                 | 19,251     | 18,403                           | 19,251     | 4,386  | 8,938      | 1,165     | 1,375     | 42,357             | 48,815     |
| Insurance                                    | 1,880                  | 2,320      | 1,207                            | 1,416      | 1,353  | 1,687      | -         | 60        | 4,440              | 5,483      |
| Meetings and Seminars                        | 20,464                 | 171,888    | 6,159                            | 10,430     | 7,782  | 19,823     | 1,055     | 1,736     | 35,460             | 203,877    |
| Office Expense                               | 264                    | 2,522      | 52                               | 1,527      | 115  | 1,605      | -         | 57        | 431                | 5,711      |
| Postage                                      | 3,841                  | 3,583      | 10,362                           | 9,159      | 1,718  | 2,606      | 7         | 93        | 15,928             | 15,441     |
| Professional Fees                            | 32,879                 | 32,993     | 21,818                           | 18,907     | 20,752   | 22,856     | -         | -         | 75,449             | 74,756     |
| Rent   | 15,289                 | 13,080     | 8,494                            | 7,984      | 6,795  | 9,513      | 340       | 340       | 30,918             | 30,917     |
| Printing                                     | 1,584                  | 5,353      | 18,484                           | 18,752     | 883  | 1,617      | -         | 26        | 20,951             | 25,748     |
| Telephone                                    | 2,172                  | 2,329      | 712                              | 1,022      | 356  | 409        | 36        | 41        | 3,276              | 3,801      |
| Research Grants                              | -                      | -          | -                                | -          | -  | -          | 48,895    | 45,158    | 48,895             | 45,158     |
| Dues and Subscriptions                       | 7,140                  | 6,025      | 4,755                            | 3,216      | 2,710  | 4,918      | 199       | 137       | 14,804             | 14,296     |
| Equipment Rental and Maintenance             | 3,137                  | 5,813      | 2,542                            | 3,548      | 4,924  | 4,227      | -         | -         | 10,603             | 13,588     |
| Total Expenses                               | \$ 329,663             | \$ 457,217 | \$ 228,867                       | \$ 212,443 | \$ 213,672                                       | \$ 217,879 | \$ 57,479 | \$ 54,012 | \$ 829,681         | \$ 941,551 |

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.  
Statements of Functional Expenses  
For the years ended December 31, 2017 and 2016

|                                  | Support Services       |           |              |           |                    |            |
|----------------------------------|------------------------|-----------|--------------|-----------|--------------------|------------|
|                                  | Management and General |           | Fund Raising |           | Comparative Totals |            |
|                                  | 2017                   | 2016      | 2017         | 2016      | 2017               | 2016       |
| Salaries, Payroll Taxes          |                        |           |              |           |                    |            |
| Employee Benefits                | \$ 20,237              | \$ 17,460 | \$ 31,801    | \$ 27,437 | \$ 52,038          | \$ 44,897  |
| Depreciation                     | 4,138                  | 3,903     | -            | -         | 4,138              | 3,903      |
| Events and Public Relations      | 583                    | 688       | 18,403       | 19,251    | 18,986             | 19,939     |
| Insurance                        | 1,739                  | 2,172     | 264          | 331       | 2,003              | 2,503      |
| Meetings and Seminars            | 20,289                 | 23,035    | 9,117        | 5,438     | 29,406             | 28,473     |
| Office Expense                   | 488                    | 638       | 546          | 3,128     | 1,034              | 3,766      |
| Postage                          | 1,942                  | 2,223     | 5,623        | 1,981     | 7,565              | 4,204      |
| Professional Fees                | 26,843                 | 5,602     | 11,680       | 6,365     | 38,523             | 11,967     |
| Rent                             | 1,359                  | 1,189     | 1,699        | 1,869     | 3,058              | 3,058      |
| Printing                         | 191                    | 179       | 5,167        | 3,917     | 5,358              | 4,096      |
| Telephone                        | 178                    | 163       | 107          | 123       | 285                | 286        |
| Research Grants                  | -                      | -         | -            | -         | -                  | -          |
| Dues and Subscriptions           | 1,411                  | 1,090     | 3,610        | 753       | 5,021              | 1,843      |
| Equipment Rental and Maintenance | 547                    | 1,399     | 71           | 830       | 618                | 2,229      |
| Total Expenses                   | \$ 79,945              | \$ 59,741 | \$ 88,088    | \$ 71,423 | \$ 168,033         | \$ 131,164 |

Cornelia de Lange Syndrome Foundation, Inc.  
Statements of Cash Flows  
For the years ended December 31, 2017 and 2016

|  | <u>2017</u>       | <u>2016</u>       |
|--|-------------------|-------------------|
| Cash flows from operating activities:  |                   |                   |
| Change in net assets   | \$ (3,686)        | \$ (52,274)       |
| Adjustments to reconcile change in net assets to<br>net cash provided by operating activities: |                   |                   |
| Depreciation and amortization  | 4,138             | 3,903             |
| Net realized and unrealized (gains) losses   | (90,736)          | (45,252)          |
| Contributions of investments   | -                 | (10,100)          |
| (Increase) decrease in:  |                   |                   |
| Promises to give   | (37,621)          | -                 |
| Inventories  | 339               | 287               |
| Prepaid expenses   | (11,607)          | -                 |
| Increase (decrease) in:  |                   |                   |
| Accrued liabilities  | (4,541)           | 3,534             |
| Net cash used by operating activities  | <u>(143,714)</u>  | <u>(99,902)</u>   |
| Cash flow from investing activities:   |                   |                   |
| Purchases of fixed assets  | (8,558)           | (5,350)           |
| Net sales (purchases) of investments   | 70,402            | (77,840)          |
| Net cash provided (used) by investing activities   | <u>61,844</u>     | <u>(83,190)</u>   |
| Net decrease in cash and equivalents   | (81,870)          | (183,092)         |
| Cash and equivalents, beginning of year  | 427,461           | 610,553           |
| Cash and equivalents, end of year  | <u>\$ 345,591</u> | <u>\$ 427,461</u> |

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, 2017 and 2016:

**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, 2017 and 2016 was \$4,138 and \$3,903, 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.

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, 2017 and 2016 the net assets of the Foundation totaled \$1,203,182 and \$1,206,868, 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:

|                                      | <u>2017</u> | <u>2016</u> |
|--------------------------------------|-------------|-------------|
| 21st Century Future Conferences Fund | \$ 91,206   | \$ 90,756   |
| 2018 National Conference             | 2,923       | -           |
| Fixed asset purchase                 | 5,549       | -           |
| Time restrictions                    | 37,621      | -           |

**3. CONTRIBUTED SERVICES AND ASSETS**

During the years ended December 31, 2017 and 2016, 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 \$-0- and \$10,099 during the years ended December 31, 2017 and 2016, respectively.

**4. UNCONDITIONAL PROMISES TO GIVE**

Unconditional promises to give are expected to be realized in one year or less and are classified as temporarily restricted net assets in the statement of activities. Unconditional promises to give amounted to \$37,621 and \$-0- at December 31, 2017 and 2016, respectively.

**5. 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.

|              | <u>2017</u> |                   | <u>2016</u> |                   |
|--------------|-------------|-------------------|-------------|-------------------|
|              | <u>Cost</u> | <u>Fair Value</u> | <u>Cost</u> | <u>Fair Value</u> |
| Mutual Funds | \$707,987   | \$812,399         | \$675,076   | \$792,065         |



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

**5. INVESTMENTS (continued)**

Investment income for the years ended December 31, 2017 and 2016 is as follows:

|                               | <u>2017</u>    | <u>2016</u>    |
|-------------------------------|----------------|----------------|
| Interest and dividend income  | \$ 15,438      | \$ 14,957      |
| Net realized gains (losses)   | 103,313        | (3,594)        |
| Net unrealized gains (losses) | (12,577)       | 48,846         |
| Investment expenses           | <u>(8,339)</u> | <u>(7,655)</u> |
| Total return                  | \$ 97,835      | \$ 52,554      |

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

|   | <u>Carrying<br/>Value</u> | <u>Fair<br/>Value</u> | <u>Excess<br/>of Fair<br/>Value<br/>Over Cost</u> |
|---|---------------------------|-----------------------|---|
| Balance at beginning of year              | \$675,076                 | \$792,065             | \$ 116,989  |
| Balance at end of year                    | <u>707,987</u>            | <u>812,399</u>        | <u>104,412</u>                                    |
| Unrealized gains (losses) for<br>the year |                           |                       | \$ <u>(12,577)</u>                                |

**6. 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. Beginning January 1, 2016, the Foundation will match employee contributions up to 2% of compensation. Pension expense was \$7,829 and \$6,239 for the years ended December 31, 2017 and 2016, respectively.

**7. FACILITY LEASE**

On April 3, 2018, the Foundation extended the terms of the current noncancelable lease agreement through February 2019 at an annual rent of \$33,975. Rent expense amounted to \$33,975 for the years ended December 31, 2017 and 2016.

The following is a schedule of future minimum rental payments required under the above operating lease as of December 31, 2017.

| <u>Year Ending December 31,</u> | <u>Amount</u> |
|---------------------------------|---------------|
| 2018                            | \$ 33,975     |
| 2019                            | 5,663         |

**8. 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).

See independent auditor's report



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

**8. TAX STATUS (continued)**

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 2014.

**9. EVALUATION OF SUBSEQUENT EVENTS**

The Organization has evaluated subsequent events through July 2, 2018, the date which the financial statements were available to be issued.