

Cornelia de Lange  
Syndrome Foundation, Inc.

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FINANCIAL STATEMENTS

For the years ended  
December 31, 2012 and 2011

Cornelia de Lange Syndrome Foundation, Inc.  
Financial Statements  
For the years ended December 31, 2012 and 2011

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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, 2012 and 2011, 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 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.

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.

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, 2012 and 2011, 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

May 7, 2013

Cornelia de Lange Syndrome Foundation, Inc.  
 Statements of Financial Position  
 December 31, 2012 and 2011

	2012	2011
<b>Assets</b>		
Current assets:		
Cash and cash equivalents	\$ 351,294	\$ 382,635
Investments	508,386	530,576
Total current assets	859,680	913,211
Equipment	149,161	142,691
Less: accumulated depreciation	(123,433)	(110,456)
Total fixed assets, net	25,728	32,235
Other asset		
Security deposit	1,230	1,230
Total assets	\$ 886,638	\$ 946,676
<b>Liabilities and Net Assets</b>		
Current liabilities:		
Accounts payable and accrued expenses	\$ 19,228	\$ 26,046
Net assets		
General funds	173,996	268,873
Board designated funds	646,808	621,437
Total unrestricted funds	820,804	890,310
Temporarily restricted net assets	46,606	30,320
Total net assets	867,410	920,630
Total liabilities and net assets	\$ 886,638	\$ 946,676

See independent accountant's audit report and notes to financial statements

Cornelia de Lange Syndrome Foundation, Inc.  
 Statements of Activities  
 For the years ended December 31, 2012 and 2011

	<u>2012</u>	<u>2011</u>
Unrestricted Net Assets		
Support		
Contributions and donations	364,605	378,699
Special events	391,273	479,490
Grants	52,124	77,804
National conference	72,589	320
Net assets released from restrictions	5,230	-
Total support revenue	<u>885,821</u>	<u>936,313</u>
Revenue		
Interest and dividend income, net of fees	10,217	13,808
Net realized and unrealized gains (losses)	49,087	(37,343)
Total revenue	<u>59,304</u>	<u>(23,535)</u>
Total support and revenue	<u>945,125</u>	<u>912,778</u>
Expenses		
Program Services (Schedule I)		
Family support	394,859	340,075
Public information and education	286,424	237,400
Professional development, outreach and awareness	196,351	212,708
Research	14,416	28,790
Total program services	<u>892,050</u>	<u>818,973</u>
Support Services (Schedule II)		
Management and general	54,543	49,085
Fundraising costs	68,038	60,227
Total support services	<u>122,581</u>	<u>109,312</u>
Total expenses	<u>1,014,631</u>	<u>928,285</u>
Change in unrestricted net assets	<u>(69,506)</u>	<u>(15,507)</u>
Temporarily Restricted Net Assets		
Contributions and grants	21,516	22,205
Net assets released from restrictions	(5,230)	-
Change in temporarily restricted net assets	<u>16,286</u>	<u>22,205</u>
Total change in net assets	<u>(53,220)</u>	<u>6,698</u>
Net assets, beginning of year	920,630	913,932
Net assets, end of year	<u>867,410</u>	<u>920,630</u>

See independent accountant's audit report and notes to financial statements

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.  
 STATEMENTS OF FUNCTIONAL EXPENSES  
 For the years ended December 31, 2012 and 2011

	<u>Program Services</u>					
	<u>Family Support Program</u>	<u>Public Information and Education</u>	<u>Professional Development, Outreach and Awareness</u>	<u>Research</u>	<u>Total Program Services</u>	<u>Comparative Totals 2011</u>
Salaries, Payroll Taxes Employee Benefits	\$ 179,771	\$ 105,951	\$ 127,197	\$ 4,721	\$ 417,640	\$ 473,301
Depreciation	-	-	-	-	-	-
Events and Public Relations	28,989	19,072	17,546	3,033	68,640	76,950
Insurance	1,387	979	847	1,092	4,305	3,970
Meetings and Seminars	110,418	91,109	11,955	4,035	217,517	65,620
Office Expense	4,653	5,675	2,491	125	12,944	11,814
Postage	5,758	6,420	7,874	-	20,052	20,463
Professional Fees	25,755	25,155	11,450	-	62,360	47,164
Rent	15,289	9,513	6,795	340	31,937	31,937
Printing	9,611	10,928	3,376	-	23,915	24,088
Telephone	3,800	1,212	875	320	6,207	7,970
Research Grants	-	-	-	-	-	25,425
Dues and Subscriptions	4,820	6,300	2,245	-	13,365	1,600
Equipment Rental and Maintenance	4,608	4,110	3,700	750	13,168	28,671
<b>Total Expenses</b>	<b>\$ 394,859</b>	<b>\$ 286,424</b>	<b>\$ 196,351</b>	<b>\$ 14,416</b>	<b>\$ 892,050</b>	<b>\$ 818,973</b>

See independent accountant's audit report and notes to the financial statements

CORNELIA DE LANGE SYNDROME FOUNDATION, INC.  
 STATEMENTS OF FUNCTIONAL EXPENSES  
 For the years ended December 31, 2012 and 2011

	Support Services			
	Management and General	Fund Raising	Total Support Services	Comparative Totals 2011
Salaries, Payroll Taxes Employee Benefits	\$ 18,565	\$ 35,967	\$ 54,532	\$ 46,810
Depreciation	12,978	-	12,978	12,210
Events and Public Relations	2,289	4,577	6,866	7,611
Insurance	144	190	334	309
Meetings and Seminars	3,722	8,240	11,962	8,019
Office Expense	3,675	955	4,630	3,998
Postage	1,300	4,120	5,420	7,681
Professional Fees	4,508	2,298	6,806	3,250
Rent	1,019	1,019	2,038	2,038
Printing	1,260	2,575	3,835	4,335
Telephone	123	156	279	308
Research Grants	-	-	-	1,602
Dues and Subscriptions	1,845	2,152	3,997	-
Equipment Rental and Maintenance	3,115	5,789	8,904	11,141
Total Expenses	\$ 54,543	\$ 68,038	\$ 122,581	\$ 109,312

See independent accountant's audit report and notes to the financial statements

Cornelia de Lange Syndrome Foundation, Inc.  
STATEMENTS OF CASH FLOWS  
For the years ended December 31, 2012 and 2011

	2012	2011
Cash flows from operating activities		
Change in net assets	\$ (53,220)	\$ 6,698
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	12,978	12,210
Net realized and unrealized (gains) losses	(49,087)	37,343
Contributions of investments	(6,185)	-
Increase (decrease) in accounts payable	(6,818)	6,948
Net cash provided (used) by operating activities	(102,332)	63,199
Cash flow from investing activities:		
Purchases of fixed assets	(6,471)	(22,546)
Net sales (purchases) of investments	77,462	(12,818)
Net cash provided (used) by investing activities	70,991	(35,364)
Net increase (decrease) in cash and equivalents	(31,341)	27,835
Cash and equivalents, beginning of year	382,635	354,800
Cash and equivalents, end of year	\$ 351,294	\$ 382,635

See independent accountant'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, 2012 and 2011:

**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 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, 2012 and 2011 was \$12,978 and \$12,210, 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, 2012 and 2011 the net assets of the Foundation totaled \$867,410 and \$920,630, 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:

	2012	2011
2012 National Conference	\$ -	\$ 5,230
21st Century Future Conferences Fund	46,606	25,090

**3. CONTRIBUTED SERVICES AND ASSETS**

During the years ended December 31, 2012 and 2011, 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 \$8,185 and \$-0- during the years ended December 31, 2012 and 2011, 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, 2012 and 2011 are summarized as follows:

	2012	2011
Mutual Funds	\$ <u>508,386</u>	<u>530,576</u>

Investment return for the years ended December 31, 2012 and 2011 is as follows:

	2012	2011
Interest and Dividend Income	\$ 15,835	\$ 19,546
Net realized & unrealized gains (losses)	49,087	(37,343)
Investment expenses	(5,618)	(5,738)
Total return	\$ 59,304	\$(23,535)

See independent accountant's audit report

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

**4. INVESTMENTS (continued)**

During the years ended December 31, 2012 and 2011, available-for-sale securities were sold for total proceeds of \$219,953 and \$127,852, respectively. The gross realized gains (losses) on these sales totaled \$10,369 and \$9,213 in 2012 and 2011 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 \$38,718 and \$(46,556) for the years ended December 31, 2012 and 2011 respectively, have been included in revenues.

**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**

In 2010 the Foundation renewed a five-year office lease expiring on February 2015, at an annual rent of \$33,975. Rent expense amounted to \$33,975 for the years ended December 31, 2012 and 2011.

The following is a schedule of future minimum rental payments required under the above operating lease as of December 31, 2012.

<u>Year Ending December 31,</u>	<u>Amount</u>
2013	\$ 33,975
2014	33,975
2015	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 2009.

**8. EVALUATION OF SUBSEQUENT EVENTS**

The Organization has evaluated subsequent events through May 7, 2013, the date which the financial statements were available to be issued.