

**NATIONAL ORGANIZATION FOR
RARE DISORDERS, INC.**

**Financial Statements
with Independent Auditor's Report**

December 31, 2012 and 2011

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

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INDEPENDENT AUDITOR'S REPORT



GUILMARTIN ▪ DIPIRO ▪ SOKOLOWSKI LLC

CERTIFIED PUBLIC ACCOUNTANTS

INDEPENDENT AUDITOR'S REPORT

The Board of Directors
National Organization for Rare Disorders, Inc.:

We have audited the accompanying financial statements of National Organization for Rare Disorders, Inc. (a nonprofit organization), which comprise the statements of financial position as of December 31, 2012 and 2011, and the related statements of activities and changes in net assets, cash flows, and functional expenses 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 audit 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 National Organization for Rare Disorders, 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.

Guilmartin, DiPiro & Sokolowski LLC

Middletown, Connecticut
August 23, 2013

FINANCIAL STATEMENTS

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Financial Position

December 31, 2012 and 2011

	<u>2012</u>	<u>2011</u>
<u>Assets</u>		
Current assets:		
Cash and cash equivalents	\$ 6,050,844	\$ 8,786,883
Certificates of deposits	1,442,005	3,252,321
Investments	303,736	343,733
Accounts receivable	344,419	339,626
Prepaid expenses	54,319	83,883
Total current assets	<u>8,195,323</u>	<u>12,806,446</u>
Non-current assets:		
Property and equipment, net	2,114,138	1,638,483
Security deposits	5,179	5,179
Total non-current assets	<u>2,119,317</u>	<u>1,643,662</u>
Total assets	<u>\$ 10,314,640</u>	<u>\$ 14,450,108</u>
<u>Liabilities and Net Assets</u>		
Current liabilities:		
Accounts payable	\$ 403,640	\$ 24,089
Accrued expenses	1,208,553	939,567
Research grants payable	841,947	574,740
Deferred revenue	68,333	35,000
Current portion of long-term debt	45,589	43,047
Total current liabilities	<u>2,568,062</u>	<u>1,616,443</u>
Long-term liabilities:		
Mortgage note payable, less current portion	647,455	693,045
Total liabilities	<u>3,215,517</u>	<u>2,309,488</u>
Net assets:		
Unrestricted	4,484,556	5,252,911
Temporarily restricted	2,614,567	6,887,709
Total net assets	<u>7,099,123</u>	<u>12,140,620</u>
Total liabilities and net assets	<u>\$ 10,314,640</u>	<u>\$ 14,450,108</u>

See accompanying notes and independent auditor's report.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Activities and Changes in Net Assets

For the years ended December 31, 2012 and 2011

	<u>2012</u>	<u>2011</u>
Unrestricted revenues, gains and other support:		
Indigent care drug and co-payment assistance programs	\$ 1,289,710	\$ 1,185,435
Special events revenue	894,199	787,050
Corporate council membership	766,750	492,975
Educational grants	707,162	453,089
Contributions and bequests	362,006	426,859
Royalties	87,846	79,915
Investment income	59,243	73,620
Membership dues	51,691	49,270
Sales and distribution of materials and services to the public	23,014	31,292
Other income	16,863	17,505
Net assets released from restrictions	<u>10,655,621</u>	<u>8,644,017</u>
Total unrestricted revenues, gains and other support	<u>14,914,105</u>	<u>12,241,027</u>
Expenses:		
Program services:		
Patient services	11,089,914	9,294,883
Education	1,997,031	1,758,596
Research	613,643	356,358
Advocacy	572,906	550,756
Technical assistance	<u>338,848</u>	<u>137,298</u>
Total program services	<u>14,612,342</u>	<u>12,097,891</u>
Supporting services:		
Management and general	620,395	585,915
Fundraising	<u>449,723</u>	<u>322,574</u>
Total supporting services	<u>1,070,118</u>	<u>908,489</u>
Total expenses	<u>15,682,460</u>	<u>13,006,380</u>
Change in unrestricted net assets	(768,355)	(765,353)
Unrestricted net assets, beginning of year	<u>5,252,911</u>	<u>6,018,264</u>
Unrestricted net assets, end of year	<u>\$ 4,484,556</u>	<u>\$ 5,252,911</u>
<u>Changes in Temporarily Restricted Net Assets</u>		
Temporarily restricted net assets, beginning of year	\$ 6,887,709	\$ 8,115,053
Contributions and grants	6,382,479	7,416,673
Net assets whose restrictions have lapsed	<u>(10,655,621)</u>	<u>(8,644,017)</u>
Temporarily restricted net assets, end of year	<u>\$ 2,614,567</u>	<u>\$ 6,887,709</u>
Total change in net assets	<u>\$ (5,041,497)</u>	<u>\$ (1,992,697)</u>

See accompanying notes and independent auditor's report.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Cash Flows

For the years ended December 31, 2012 and 2011

	<u>2012</u>	<u>2011</u>
Cash flows from operating activities:		
Change in net assets	<u>\$ (5,041,497)</u>	<u>\$ (1,992,697)</u>
Adjustments to reconcile net (loss) to net cash (used) in operating activities:		
Depreciation	184,944	126,443
Donated investments	(6,545)	(6,059)
Decrease (increase) in certificates of deposits	1,810,316	(20,717)
Realized and unrealized (gain) loss on investments	(11,813)	12,206
(Increase) in accounts receivable, net	(4,793)	(115,950)
Decrease in prepaid expenses	29,564	3,453
Increase (decrease) in accounts payable	379,551	(58,312)
Increase in accrued expenses	268,986	18,711
Increase in research grants payable	267,207	56,249
Increase (decrease) in deferred revenue	<u>33,333</u>	<u>(176,370)</u>
Total adjustments	<u>2,950,750</u>	<u>(160,346)</u>
Net cash (used) in operating activities	<u>(2,090,747)</u>	<u>(2,153,043)</u>
Cash flows from investing activities:		
Purchase of building, property and equipment	(660,599)	(142,907)
Proceeds on sale of investments	<u>58,355</u>	<u>168,907</u>
Net cash (used) in provided by investing activities	<u>(602,244)</u>	<u>26,000</u>
Cash flows from financing activities:		
Payments on long-term debt	<u>(43,048)</u>	<u>(40,648)</u>
Net cash (used) in financing activities	<u>(43,048)</u>	<u>(40,648)</u>
Net (decrease) in cash and cash equivalents	<u>(2,736,039)</u>	<u>(2,167,691)</u>
Cash and cash equivalents, beginning of year	<u>8,786,883</u>	<u>10,954,574</u>
Cash and cash equivalents, end of year	<u>\$ 6,050,844</u>	<u>\$ 8,786,883</u>
Non-cash investing activities:		
Donated investments	<u>\$ 6,545</u>	<u>\$ 6,059</u>

See accompanying notes and independent auditor's report.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Functional Expenses

For the year ended December 31, 2012

	Program Services					Supporting Services			Total Expenses	
	Patient Services	Education	Technical Assistance	Research	Advocacy	Total	Management and General	Fundraising		Total
Research grants and programs	\$ 10,065,450	\$ 67,696	\$ -	\$ 522,475	\$ -	\$ 10,655,621	\$ -	\$ -	\$ -	\$ 10,655,621
Salaries	497,941	765,590	192,699	65,500	383,677	1,905,407	399,858	60,923	460,781	2,366,188
Facilities	120,688	222,791	28,205	11,655	39,500	422,839	61,127	7,398	68,525	491,364
Professional fees	174,142	121,084	46,664	-	7,603	349,493	21,501	23,891	45,392	394,885
Travel and meeting expenses	42,737	202,819	9,810	-	65,502	320,868	5,711	51,705	57,416	378,284
Employee benefits	59,059	107,216	13,971	5,900	33,221	219,367	46,681	13,814	60,495	279,862
Conferences and patient travel	2,710	273,663	-	-	-	276,373	-	-	-	276,373
Special events	-	-	-	-	-	-	-	-	-	-
Payroll taxes	45,237	65,397	17,996	5,850	23,722	158,202	34,178	6,086	40,264	198,466
Office supplies and expense	35,188	49,395	4,476	998	4,658	94,715	7,296	26,002	33,298	128,013
Data systems	17,394	26,655	17,969	1,265	3,447	66,730	20,481	4,836	25,317	92,047
Marketing	1,179	50,191	1,208	-	3	52,581	-	27,797	27,797	80,378
Dues, subscriptions and registrations	2,885	23,997	1,176	-	8,452	36,510	3,975	18,089	22,064	58,574
Insurance	11,001	10,702	2,598	-	2,865	27,166	5,427	843	6,270	33,436
Employee related costs	1,269	4,642	1,961	-	174	8,046	3,586	129	3,715	11,761
Corporate council expense	-	-	-	-	17	17	-	3,623	-	3,640
Miscellaneous	13,034	5,193	115	-	65	18,407	10,574	325	10,899	29,306
Total functional expenses	\$ 11,089,914	\$ 1,997,031	\$ 338,848	\$ 613,643	\$ 572,906	\$ 14,612,342	\$ 620,395	\$ 449,723	\$ 1,070,118	\$ 15,682,460

See accompanying notes and independent auditor's report.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Functional Expenses

For the year ended December 31, 2011

	Program Services					Supporting Services			Total Expenses
	Patient Services	Education	Technical Assistance	Research	Advocacy	Total	Management and General	Fundraising	
Research grants and programs	\$ 8,350,403	\$ 163,221	\$ -	\$ 270,583	\$ -	\$ 8,784,207	\$ -	\$ -	\$ 8,784,207
Salaries	489,707	680,875	61,850	62,000	276,527	1,570,959	386,831	199,720	586,551
Facilities	104,520	93,700	10,596	10,596	121,802	341,214	64,585	7,562	72,147
Professional fees	131,983	65,730	8,334	-	70,780	276,827	4,869	66,305	71,174
Employee benefits	101,860	103,863	5,633	5,633	26,886	243,875	55,813	14,850	70,663
Conferences and patient travel	-	289,237	-	-	-	289,237	-	-	-
Payroll taxes	38,839	65,707	5,062	5,576	14,487	129,671	32,066	8,166	40,232
Travel and meeting expenses	10,334	105,863	91	-	10,340	126,628	4,320	5,477	9,797
Marketing	8,810	90,272	8,110	-	-	107,192	-	3,513	110,705
Office supplies and expense	32,853	23,274	2,711	1,100	4,661	64,599	9,602	2,292	11,894
Dues, subscriptions and registrations	3,188	10,324	628	-	22,981	37,121	2,480	12,438	14,918
Data systems	-	15,197	29,707	870	656	46,430	-	-	-
Insurance	10,596	9,432	2,256	-	1,428	23,712	5,652	708	30,072
Corporate council expense	-	27,154	-	-	-	27,154	-	-	27,154
Utilities	7,921	8,791	1,706	-	-	18,418	5,149	586	24,153
Employee related costs	3,743	4,074	614	-	208	8,639	5,420	952	15,011
Miscellaneous	126	1,882	-	-	-	2,008	9,128	5	11,141
Total functional expenses	\$ 9,294,883	\$ 1,758,596	\$ 137,298	\$ 356,358	\$ 550,756	\$ 12,097,891	\$ 585,915	\$ 322,574	\$ 908,489
									\$ 13,006,380

See accompanying notes and independent auditor's report.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements

December 31, 2012 and 2011

NOTE 1

SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of activities

The National Organization for Rare Disorders, Inc. (NORD or the Organization) is a not-for-profit organization incorporated on May 4, 1983, under the laws of the State of New York.

NORD was formed to create a clearinghouse for information on rare disorders; to aid government agencies in activities pursuant to the Orphan Drug Act; to encourage and promote increased scientific and clinical research on rare disorders; and to provide services to patients and their families, especially to enhance their access to medical treatment for their diseases. NORD manages both indigent care drug programs that provide medication at no cost to those in need and financial hardship relief programs to provide individuals that meet objective criteria, with insurance premium and co-payment assistance through funds provided by various pharmaceutical companies.

Basis of presentation

The accompanying financial statements have been prepared on the accrual method of accounting in accordance with generally accepted accounting principles as accepted in the United States (referred to as GAAP).

Income tax status

NORD has received exemption from federal income tax under Section 501(c)(3) of the Internal Revenue Code. The Organization has also been classified as an entity that is not a private foundation within the meaning of Section 509(a) and qualifies for deductible contributions as provided in Section 170(b)(1)(a)(vi).

Management has reviewed the Organization's reporting and believe they have not taken tax positions that are more likely than not to be determined to be incorrect by the Internal Revenue Service and therefore no adjustments or disclosures are required.

Estimates

The preparation of financial statements requires management to make estimates and assumptions that affect the certain reported amounts. Accordingly actual results could differ from those estimates.

Cash and cash equivalents

For the purpose of the statements of cash flows, the Organization considers all highly liquid investments with an original maturity of three months or less to be cash equivalents.

Allowance for bad debts

The allowance for doubtful accounts is based on management's evaluation of specific accounts receivable at the end of the year. Receivables are written off to the allowance when it is probable that the Organization will not collect the receivable. There were no allowances as of December 31, 2012 and 2011.

Property and equipment

NORD follows the practice of capitalizing all property and equipment with a cost exceeding \$500. Depreciation is computed using the straight-line method over the estimated useful lives of the assets with a range in lives from 3 to 30 years. There are no planned major maintenance activities.

Net assets

To ensure observance of limitations and restrictions placed on the use of resources available to the Organization, the limitations and restrictions are maintained in the following net asset categories:

Unrestricted

The Organization's unrestricted net assets are for general use by the corporation.

Temporarily restricted

Temporarily restricted net assets represent contributions and other resources that are restricted by the donor either as to purpose or as to time of expenditure.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements

December 31, 2012 and 2011

Temporarily restricted, continued

Temporarily restricted net assets are available to provide services to patients and their families, especially to enhance their access to medical treatment for their diseases, and for disease specific research grants, as specified by the donors. Net assets were released from donor restrictions by incurring expenses satisfying the restricted purposes as specified by the donors.

The Organization reports gifts of cash and other assets as temporarily restricted support if they are received with donor stipulations that limit the use of the donated assets. When a donor restriction expires, that is, when a stipulated time restriction expires or a purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statements of activities and changes in net assets as net assets released from restrictions.

Permanently restricted

Permanently restricted net assets represent contributions that are so restricted that neither the passage of time nor actions by the Organization can fulfill the restriction. There were no permanently restricted net assets as of December 31, 2012.

Reclassifications

Certain line items in the fiscal year 2011 statements of activities and changes in net assets have been adjusted in order to conform to the presentation of the fiscal year 2012 amounts.

NOTE 2

CONCENTRATIONS

During the years ended December 31, 2012 and 2011, the Organization had one donor who represented 24% and 23%, respectively of their revenues.

The Organization maintains their cash balances with various financial institutions. Such deposits at times have exceeded federal depository limits; however, the Organization believes its cash deposits are not subject to significant credit risk.

NOTE 3

INVESTMENTS

All investments are available for sale and transfer to support Organization requirements (including Board designations) and presented on the financial statements at fair market value. Generally accepted accounting principles have determined that short-term and long-term investments traded on the open market (individual stocks, ETF's and mutual funds) are determined by reference to quoted prices of identical instruments generated by active market transactions and are considered to be level one transactions. All of the Organization's investments are considered to be level one.

The following schedule reflects the market value of investments at December 31:

	<u>2012</u>	<u>2011</u>
Equities and mutual funds	\$303,736	\$ 53,307
Corporate bonds	-	290,426
	<u>\$303,736</u>	<u>\$343,733</u>

NOTE 4

PROPERTY AND EQUIPMENT

Components of property and equipment at December 31 are as follows:

	<u>2012</u>	<u>2011</u>
Furniture and equipment	\$ 1,494,589	\$1,243,363
Land	493,750	493,750
Land improvements	11,500	11,500
Building	744,750	744,750
Building improvements	23,015	16,800
Leasehold improvements	11,910	11,910
Capital in progress	403,157	-
Less: accumulated depreciation	<u>(1,068,533)</u>	<u>(883,590)</u>
Total	<u>\$ 2,114,138</u>	<u>\$1,638,483</u>

The financial statements reflect depreciation expense of \$184,944 and \$126,443 for the years ended December 31, 2012 and 2011, respectively.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements

December 31, 2012 and 2011

NOTE 5

DEBT OBLIGATIONS

The Organization has a mortgage payable to a bank with an annual interest rate of 5.75% through February 2024, secured by the Organization's office building. The balance outstanding on this mortgage was \$693,044 and \$736,092 as of December 31, 2012 and 2011, respectively.

Interest expense incurred on the mortgage for the years ended December 31, 2012 and 2011 was \$41,203 and \$43,602, respectively.

Maturities of the mortgage payable for the next five years are as follows:

2013	\$ 45,589
2014	48,281
2015	51,131
2016	54,150
2017	57,347

NOTE 6

TEMPORARILY RESTRICTED NET ASSETS

Community directed donations

The Organization has developed a financial hardship relief program that provides insurance premium assistance and co-payment assistance for individuals meeting objective criteria. In connection with this program, the Organization has entered into agreements with several pharmaceutical companies, whereby NORD will make payments to individuals from the community directed donations. The amount of contributions received under these programs was \$6,382,479 and \$7,416,673 in 2012 and 2011, respectively and such contributions are considered temporarily restricted funds.

NOTE 7

OPERATING LEASES

The Organization leases certain office space in Washington D.C. and Quincy, Massachusetts under non-cancelable operating leases expiring in May 2014 and December 2017, respectively. The leases have renewal options and, in addition to the base rent, are also subject to a pro rata share of certain operating expenses.

The total base rental operating lease payments under these non-cancelable leases are as follows:

2013	\$155,539
2014	115,576
2015	88,080
2016	91,750
2017	95,420

NOTE 8

DEFINED CONTRIBUTION PLAN

The Organization maintains a 403(b) plan for most employees. Employer contributions are equal to 5% of the employee's regular annual compensation. Contributions for the years ended December 31, 2012 and 2011 were \$74,905 and \$85,388, respectively.

NOTE 9

SUBSEQUENT EVENTS

Management has evaluated subsequent events through August 23, 2013, the date on which the financial statements were available to be issued.