

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

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

December 31, 2011

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Table of Contents

	<u>Page</u>
INDEPENDENT AUDITOR'S REPORT	1
FINANCIAL STATEMENTS	
Statement of Financial Position	2
Statement of Activities	3
Statement of Cash Flows	4
Statement of Functional Expenses	5
Notes to Financial Statements	6

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 statement of financial position of National Organization for Rare Disorders, Inc. (a nonprofit organization) as of December 31, 2011, and the related statements of activities, cash flows and functional expenses for the year then ended. These financial statements are the responsibility of the Organization's management. Our responsibility is to express an opinion on these financial statements based on our audit. The financial statements of National Organization for Rare Disorders, Inc. as of December 31, 2010 were audited by Solakian, Caiafa & Company, LLC whose report dated May 9, 2011 expressed an unqualified opinion on those statements. We also audited the adjustments described in Note 9 that were applied to restate the December 31, 2010 financial statements. In our opinion, such adjustments are appropriate and have been properly applied.

We conducted our audit 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 of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our 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, 2011, and the changes in its net assets and its cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America.

Guilmartin, DiPiro + Sokolowski, LLC

Middletown, Connecticut
June 6, 2012

FINANCIAL STATEMENTS

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Financial Position

December 31, 2011

Assets

Current assets:	
Cash and cash equivalents	\$ 8,786,883
Certificates of deposits	3,252,321
Investments	343,733
Accounts receivable	339,626
Prepaid expenses	83,883
Total current assets	<u>12,806,446</u>
Non-current assets:	
Property and equipment, net	1,638,483
Security deposits	5,179
Total non-current assets	<u>1,643,662</u>
Total assets	<u>\$ 14,450,108</u>

Liabilities and Net Assets

Current liabilities:	
Accounts payable	\$ 24,089
Accrued expenses	939,567
Research grants payable	574,740
Deferred revenue	35,000
Current portion of long-term debt	43,047
Total current liabilities	<u>1,616,443</u>
Long-term liabilities:	
Mortgage note payable, less current portion	<u>693,045</u>
Total liabilities	<u>2,309,488</u>
Net assets:	
Unrestricted	5,252,911
Temporarily restricted	6,887,709
Total net assets	<u>12,140,620</u>
Total liabilities and net assets	<u>\$ 14,450,108</u>

See accompanying notes and independent auditor's report.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Activities

For the year ended December 31, 2011

Unrestricted revenues, gains and other support:	
Indigent care drug and co-payment assistance programs	\$ 1,185,435
Contributions and bequests	1,117,256
Special events revenue, net	589,628
Educational grants	459,089
Royalties	79,915
Investment income	73,620
Membership dues	49,270
Sales and distribution of materials and services to the public	31,292
Other income	11,505
Net assets released from restrictions	<u>8,644,017</u>
Total revenues, gains and other support	<u>12,241,027</u>
Expenses:	
Program Services:	
Patient services	9,294,883
Education	1,758,596
Technical assistance	137,298
Research	356,358
Advocacy	<u>550,756</u>
Total program services	<u>12,097,891</u>
Supporting Services:	
Management and general	585,915
Fundraising	<u>322,574</u>
Total supporting services	<u>908,489</u>
Total expenses	<u>13,006,380</u>
Change in unrestricted net assets	(765,353)
Unrestricted net assets, beginning of year, as restated	<u>6,018,264</u>
Unrestricted net assets, end of year	<u>\$ 5,252,911</u>
<u>Changes in Temporarily Restricted Net Assets</u>	
Temporarily restricted net assets, beginning of year, as restated	\$ 8,115,053
Contributions and grants	7,416,673
Net assets whose restrictions have lapsed	<u>(8,644,017)</u>
Temporarily restricted net assets, end of year	<u>\$ 6,887,709</u>
Total change in net assets	<u>\$ (1,992,697)</u>

See accompanying notes and independent auditor's report.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Cash Flows

For the year ended December 31, 2011

Cash flows from operating activities:	
Change in net assets	\$ (1,992,697)
Adjustments to reconcile net income to net cash provided (used) by operating activities:	
Depreciation	126,443
Donated investments	(6,059)
(Increase) in certificates of deposits	(20,717)
Realized and unrealized loss on investments	12,206
(Increase) in accounts receivable, net	(115,950)
Decrease in prepaid expenses	3,453
(Decrease) in accounts payable	(58,312)
(Decrease) in accrued expenses	18,711
Increase in research grants payable	56,249
(Decrease) in deferred revenue	(176,370)
Total adjustments	(160,346)
Net cash (used) in operating activities	(2,153,043)
Cash flows from investing activities:	
Purchase of building, property and equipment	(142,907)
Proceeds on sale of investments	168,907
Net cash provided by investing activities	26,000
Cash flows from financing activities:	
Payments on long-term debt	(40,648)
Net cash (used) in financing activities	(40,648)
Net (decrease) in cash and cash equivalents	(2,167,691)
Cash and cash equivalents, beginning of year	10,954,574
Cash and cash equivalents, end of year	\$ 8,786,883
Non-cash investing activities:	
Donated investments	\$ 6,059

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			
	Patient Services	Education	Technical Assistance	Research	Advocacy	Management and General	Fundraising	Total	Total Expenses
Research grants and programs	\$ 8,350,403	\$ 163,221	\$ -	\$ 270,583	\$ -	\$ -	\$ -	\$ -	\$ 8,784,207
Salaries	489,707	680,875	61,850	62,000	276,527	386,831	199,720	586,551	2,157,510
Professional fees	131,983	65,730	8,334	-	70,780	4,869	66,305	71,174	348,001
Employee benefits	101,860	103,863	5,633	5,633	26,886	55,813	14,850	70,663	314,538
Conferences and patient travel	-	289,237	-	-	-	-	-	-	289,237
Payroll taxes	38,839	65,707	5,062	5,576	14,487	32,066	8,166	40,232	169,903
Facilities	104,520	93,700	10,596	10,596	121,802	64,585	7,562	72,147	413,361
Travel and meeting expenses	10,334	105,863	91	-	10,340	4,320	5,477	9,797	136,425
Marketing	8,810	90,272	8,110	-	-	-	3,513	3,513	110,705
Employee related costs	3,743	4,074	614	-	208	5,420	952	6,372	15,011
Corporate council expense	-	27,154	-	-	-	-	-	-	27,154
Dues, subscriptions and registrations	3,188	10,324	628	-	22,981	2,480	12,438	14,918	52,039
Office supplies and expense	32,853	23,274	2,711	1,100	4,661	9,602	2,292	11,894	76,493
Insurance	10,596	9,432	2,256	-	1,428	5,652	708	6,360	30,072
Utilities	7,921	8,791	1,706	-	-	5,149	586	5,735	24,153
Data systems	-	15,197	29,707	870	656	-	-	-	46,430
Miscellaneous	126	1,882	-	-	-	9,128	5	9,133	11,141
Total functional expenses	\$ 9,294,883	\$ 1,758,596	\$ 137,298	\$ 356,358	\$ 550,756	\$ 585,915	\$ 322,574	\$ 908,489	\$ 13,006,380

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements

December 31, 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).

The 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 statement 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.

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, 2011

Temporarily restricted, continued

Temporarily restricted net assets are available 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 statement of activities 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, 2011.

Reclassification

Certain prior year amounts have been reclassified to conform with the presentation in the current year financial statements.

NOTE 2

CONCENTRATIONS

During the year ended December 31, 2011, the Organization had one donor who represented 23% 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:

Equities and mutual funds	\$ 53,307
Corporate bonds	<u>290,426</u>
	<u>\$343,733</u>

NOTE 4

PROPERTY AND EQUIPMENT

Components of property and equipment are as follows:

Furniture and equipment	\$1,243,363
Land	493,750
Land improvements	11,500
Building	744,750
Building improvements	16,800
Leasehold improvements	11,910
Less: accumulated depreciation	<u>(883,590)</u>
Total	<u>\$1,638,483</u>

The financial statements reflect depreciation expense of \$126,443 as of December 31, 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 \$736,092 as of December 31, 2011.

Interest expense incurred on the mortgage for the year ending December 31, 2011 was \$43,602.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements

December 31, 2011

Debt obligations, continued

The following are the maturities of the mortgage payable for the next five years:

2012	\$ 43,047
2013	45,589
2014	48,281
2015	51,131
2016	54,150
Thereafter	<u>493,894</u>
Total	<u>\$736,092</u>

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 \$7,416,673 in 2011 and such contributions are considered temporarily restricted funds.

NOTE 7

OPERATING LEASES

The Organization leases certain office space in Washington D.C. under a non-cancelable operating lease expiring in May 2014. The lease has renewal options and, in addition to the base rent, is also subject to a pro rata share of certain operating expenses.

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

2012	\$74,799
2013	74,799
2014	31,166

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 year ended December 31, 2011 were \$85,388.

NOTE 9

RESTATEMENT

The unrestricted net assets at December 31, 2010 excluded accounts receivable balances, accounts payable, accrued vacation days, accrued payroll and taxes, accrued audit fees, accrued patient fees and net assets released from restrictions. Unrestricted net assets also included property and equipment which was abandoned as of December 31, 2010.

Beginning balance	\$6,074,123
Accounts receivable	125,875
Property and equipment	(83,576)
Accounts payable	(52,058)
Accrued vacation	(25,818)
Accrued payroll and taxes	(8,282)
Accrued audit fees	(12,000)
Accrued patient fees	(783,260)
Net assets released from restrictions	<u>783,260</u>
Unrestricted net assets, as restated	<u>\$6,018,264</u>

The temporarily restricted net assets at December 31, 2010 included net assets that were released from restrictions as of December 31, 2010.

Beginning balance	\$8,898,313
Net assets released from restrictions	<u>(783,260)</u>
Temporarily restricted net assets, as restated	<u>\$8,115,053</u>

NOTE 10

SUBSEQUENT EVENTS

Management has evaluated subsequent events through June 6, 2012, the date on which the financial statements were available to be issued.