

FINANCIAL STATEMENTS
DECEMBER 31, 2013
TOGETHER WITH
INDEPENDENT AUDITOR'S REPORT

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Where Every Client Is A Valued Client

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INDEPENDENT AUDITOR'S REPORT

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

#### Report on the Financial Statements

We have audited the accompanying financial statements of National Organization for Rare Disorders, Inc. (a New York corporation, not for profit) which comprise the statement of financial position as of December 31, 2013, and the related statements of activities, changes in net assets, cash flows and functional expenses for the year 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 audit. 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 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, 2013, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Alexander, arenson, Finning & Co. P.C. Boston, Massachusetts

May 9, 2014

# STATEMENT OF FINANCIAL POSITION DECEMBER 31, 2013

<u>ASSETS</u>	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL
CURRENT ASSETS:			
Cash	\$ 3,816,336	\$ 1,657,286	\$ 5,473,622
Certificates of deposit	833,632	Ψ 1,037,260	833,632
Investments	275,903	_	275,903
Accounts receivable	1,787,467	266,342	2,053,809
Prepaid expenses	104,835	200,542	104,835
r repaid expenses	104,633		104,833
Total current assets	6,818,173	1,923,628	8,741,801
CERTIFICATE OF DEPOSIT	613,207	-	613,207
PROPERTY AND EQUIPMENT, net	1,647,298	-	1,647,298
SOFTWARE UNDER DEVELOPMENT	752,712	_	752,712
Total assets	\$ 9,831,390	\$ 1,923,628	\$ 11,755,018
LIABILITIES AND NET ASSETS			
CURRENT LIABILITIES:			
Current portion of long-term debt	\$ 50,309	\$ -	¢ 50.200
Accounts payable	287,159	φ -	\$ 50,309
Accrued expenses	1,883,237	=	287,159
Research grants payable	831,378	-	1,883,237
Deferred revenue	*	-	831,378
Deferred revenue	1,774,069		1,774,069
Total current liabilities	4,826,152	-	4,826,152
LONG TERM DEBT, less current portion	596,213	-	596,213
Total liabilities	5,422,365		5,422,365
NET ASSETS:			
Unrestricted:			
Operating	2,009,015		2 000 015
Property, equipment and software under development		-	2,009,015
Troperty, equipment and software under development	2,400,010		2,400,010
Total unrestricted	4,409,025	-	4,409,025
Temporarily restricted		1,923,628	1,923,628
Total net assets	4,409,025	1,923,628	6,332,653
Total liabilities and net assets	\$ 9,831,390	\$ 1,923,628	\$ 11,755,018

# STATEMENT OF ACTIVITIES FOR THE YEAR ENDED DECEMBER 31, 2013

	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL
OPERATING REVENUES AND SUPPORT:			
Program grants	\$ 930,257	\$ 12,160,568	\$ 13,090,825
Patient assistance and research program fees	1,418,853	-	1,418,853
Special events revenue	776,744	-	776,744
Membership dues	751,040	-	751,040
Contributions and bequests	617,280	-	617,280
Royalties and other	146,154	-	146,154
Interest income	18,998	-	18,998
Net assets released from purpose restrictions	12,419,386	(12,419,386)	
Total operating revenues and support	17,078,712	(258,818)	16,819,894
OPERATING EXPENSES:			
Program services:			
Patient services	12,459,521	-	12,459,521
Advocacy	385,505	-	385,505
Research and medical & scientific affairs	620,136	- -	620,136
Membership and education	708,174		708,174
Total program services	14,173,336		14,173,336
Support services:			
General and administrative	2,117,125	-	2,117,125
Development and communications	1,308,380		1,308,380
Total support services	3,425,505		3,425,505
Total operating expenses	17,598,841	_	17,598,841
Changes in net assets from operations	(520,129)	(258,818)	(778,947)
NET GAIN ON INVESTMENTS	12,477		12,477
Changes in net assets	\$ (507,652)	\$ (258,818)	\$ (766,470)

# STATEMENT OF CHANGES IN NET ASSETS FOR THE YEAR ENDED DECEMBER 31, 2013

	UNRESTRICTED	TEMPORARILY RESTRICTED	<b>TOTAL</b>
NET ASSETS, December 31, 2012	\$ 4,484,556	\$ 2,614,567	\$ 7,099,123
Prior period adjustment	432,121	(432,121)	
NET ASSETS, December 31, 2012, as restated	4,916,677	2,182,446	7,099,123
Changes in net assets	(507,652)	(258,818)	(766,470)
NET ASSETS, December 31, 2013	\$ 4,409,025	\$ 1,923,628	\$ 6,332,653

### STATEMENT OF CASH FLOWS FOR THE YEAR ENDED DECEMBER 31, 2013

CASH FLOWS FROM OPERATING ACTIVITIES:	
Changes in net assets	\$ (766,470)
Adjustments to reconcile changes in net assets	
to net cash used in operating activities:	
Depreciation	197,693
Donated investments	(5,579)
Net gain on investments	(12,477)
Changes in operating assets and liabilities:	
Accounts receivable	(1,709,390)
Prepaid expenses	(45,337)
Accounts payable	(234,724)
Accrued expenses	674,684
Research grants payable	(10,569)
Deferred revenue	1,705,736
Net cash used in operating activities	(206,433)
CASH FLOWS FROM INVESTING ACTIVITIES:	
Reinvested interest earned on certificates of deposit	(4,834)
Proceeds from sales of investments	45,888
Investment in software under development	(316,373)
Acquisition of property and equipment	(48,948)
Net cash used in investing activities	(324,267)
CASH FLOWS FROM FINANCING ACTIVITY:	
Principal payments on long-term debt	(46,522)
	(,)
NET DECREASE IN CASH	(577,222)
CASH, beginning of year	6,050,844
CASH, end of year	\$ 5,473,622
SUPPLEMENTAL DISCLOSURE OF NON-CASH TRANSACTION:	
Donated investments	\$ 5,579
Software under development financed through accounts payable	\$ 118,242
SUPPLEMENTAL DISCLOSURES OF CASH FLOW INFORMATION:	
Cash paid for interest	¢ 26.210
Cash paid for interest	\$ 36,319

# STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED DECEMBER 31, 2013

	PROGRAM SERVICES			SUPPORT SERVICES					
			RESEARCH AND			GENERAL			
	PATIENT SERVICES	ADVOCACY	MEDICAL & SCIENTIFIC AFFAIRS	MEMBERSHIP AND EDUCATION	TOTAL PROGRAM <u>SERVICES</u>	AND ADMINIS- TRATIVE	DEVELOPMENT AND COMMUNICATIONS	TOTAL SUPPORT SERVICES	TOTAL EXPENSES
PROGRAM GRANTS	\$ 11,826,511	\$ -	\$ 255,000	\$ -	\$ 12,081,511	\$ -	_\$	_\$	\$ 12,081,511
PERSONNEL AND RELATED:									
Salaries	381,262	150,091	238,244	236,550	1,006,147	1,286,755	362,313	1,649,068	2,655,215
Payroll taxes and fringe benefits	77,652	38,056	34,895	49,229	199,832	260,943	75,316	336,259	536,091
Employee related costs	898	263	289	325	1,775	7,175	1,434	8,609	10,384
				-					10,00
Total personnel and related	459,812	188,410	273,428	286,104	1,207,754	1,554,873	439,063	1,993,936	3,201,690
OCCUPANCY:									
Rent	80	52,320	14,038	_	66,438	98,940	44,141	143,081	209,519
Utilities, equipment and storage	19,053	5,814	5,043	7,209	37,119	34,529	17,871	52,400	89,519
Repairs and maintenance	14,279	526	3,031	2,963	20,799	21,414	10,627	32,041	52,840
Interest	9,911	_	1,794	1,522	13,227	14,985	8,107	23,092	36,319
Property insurance	5,459	1,442	2,884	2,575	12,360	10,815	3,605	14,420	26,780
Total occupancy	48,782	60,102	26,790	14,269	149,943	180,683	84,351	265,034	414,977
OTHER:									
Travel and meeting	8,414	17,567	21,960	347,317	395,258	87,143	19,724	106,867	502,125
Professional fees	24,748	93,216	10,249	2,599	130,812	93,174	134,619	227,793	358,605
Special events	, -	, <u> </u>	-	-,	,	-	313,035	313,035	313,035
Office supplies	33,761	3,204	2,117	17,560	56,642	15,248	91,992	107,240	163,882
Marketing	29	793	452	903	2,177	362	144,748	145,110	147,287
Data systems	8,509	8,252	3,409	6,475	26,645	75,484	37,335	112,819	139,464
Dues, subscriptions and registrations	55	2,697	4,155	-	6,907	8,447	9,113	17,560	24,467
Conferences and patient travel	4,500	50	285	15,269	20,104	1,155	2,454	3,609	23,713
Miscellaneous	269	100	101	-	470	14,822	1,367	16,189	16,659
Insurance	2,799	740	1,479	1,320	6,338	5,546	1,849	7,395	13,733
Total other	83,084	126,619	44,207	391,443	645,353	301,381	756,236	1,057,617	1,702,970
Total operating expenses before depreciation	12,418,189	375,131	599,425	691,816	14,084,561	2,036,937	1,279,650	3,316,587	17,401,148
Depreciation	41,332	10,374	20,711	16,358	88,775	80,188	28,730	108,918	197,693
Total operating expenses	\$ 12,459,521	\$ 385,505	\$ 620,136	\$ 708,174	\$ 14,173,336	\$ 2,117,125	\$ 1,308,380	\$ 3,425,505	\$ 17,598,841

#### NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2013

#### (1) OPERATIONS, NONPROFIT STATUS AND SIGNIFICANT ACCOUNTING POLICIES

#### **OPERATIONS AND NONPROFIT STATUS**

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

NORD was formed to provide information on rare disorders and related resources, to aid government agencies in activities pursuant to the Orphan Drug Act, to encourage and promote increased scientific and clinical research on rare disorders, to support and mentor disease-specific patient organizations, 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 who meet objective criteria with insurance premium and co-payment assistance through funds provided by various pharmaceutical companies.

NORD's main office is in Danbury, Connecticut, with additional offices in Massachusetts and Washington, D.C.

NORD is exempt from Federal income taxes as an organization (not a private foundation) formed for charitable purposes under Section 501(c)(3) of the Internal Revenue Code (IRC). NORD is also exempt from state income taxes. Donors may deduct contributions made to NORD within the requirements of the IRC.

#### SIGNIFICANT ACCOUNTING POLICIES

NORD's financial statements have been prepared in accordance with accounting standards generally accepted in the United States of America (U.S. GAAP). References to U.S. GAAP and ASC in these footnotes are to the FASB Accounting Standards Codification.

#### Certificates of Deposit

The certificates of deposit at December 31, 2013, mature at various dates through September, 2015. Those maturing within the next fiscal year are shown as current in the accompanying statement of financial position.

#### Accounts Receivable and Allowance for Doubtful Accounts

Accounts receivable at December 31, 2013, consist mainly of amounts due for program services. The allowance for doubtful accounts is based on collection experience and other circumstances which may affect the ability of NORD to collect. No allowance was deemed necessary at December 31, 2013.

#### **Investments**

The primary investment objective is to earn a total rate of return modestly greater than provided by general savings accounts and protecting assets while earning a return. Investment allocations are reviewed by NORD on a semi-annual basis and adjustments are made, when necessary.

#### NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2013

(Continued)

# (1) <u>OPERATIONS, NONPROFIT STATUS AND SIGNIFICANT ACCOUNTING POLICIES</u> (Continued)

#### **SIGNIFICANT ACCOUNTING POLICIES (Continued)**

#### Fair Value Measurements

NORD follows the *Fair Value Measurements and Disclosures* standards. These standards define fair value, establish a framework for measuring fair value under U.S. GAAP, and mandate disclosures about fair value measurements. The three levels of the fair value hierarchy are as follows:

- ➤ Level 1 Inputs that reflect unadjusted quoted prices in active markets for identical assets at the measurement date.
- ➤ Level 2 Inputs other than quoted prices in active markets that are observable for the asset either directly or indirectly, including inputs in markets that are not considered to be active.
- ➤ Level 3 Inputs that are unobservable.

A qualifying asset or liability's level within the framework is based upon the lowest level of any input that is significant to the fair value measurement. NORD values all its qualified assets and liabilities using Level 1 inputs.

#### Property and Equipment and Depreciation

Property and equipment (see Note 3) are recorded at cost when purchased or at fair value at the time of donation. Renewals and betterments are capitalized, while repairs and maintenance are expensed as they are incurred.

Depreciation is computed using the straight-line method over the following estimated useful lives:

	<u>Useful Lives</u>
Computers and computer software	5 - 10 years 20 - 40 years 5 years Term of lease

#### Software Under Development

Software under development includes the cost of developing a system to track and monitor patient expenses. Costs related to software or modules not placed in service as of December 31, 2013, are \$752,712 and are reflected as software under development in the accompanying statement of financial position.

#### Research Grants Payable

Research grants are recorded when awarded by NORD. Payments are made when all conditions of the grant are met by the grantee. Research grants expected to be paid during the subsequent fiscal year are shown as current liabilities in the accompanying statement of financial position.

#### NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2013

(Continued)

# (1) <u>OPERATIONS, NONPROFIT STATUS AND SIGNIFICANT ACCOUNTING POLICIES</u> (Continued)

#### **SIGNIFICANT ACCOUNTING POLICIES (Continued)**

#### Deferred Revenue

Deferred revenue consists of membership revenue received in advance of the membership effective date.

#### Net Assets

#### **Unrestricted Net Assets**

Unrestricted net assets are those net resources that bear no external restrictions and are generally available for use by NORD. NORD has grouped its unrestricted net assets into the following categories:

*Operating* - Represents resources available to carry on the operations of NORD.

**Property, equipment and software under development** - Represent the activities relating to NORD's property, equipment and software under development, net of related debt.

#### **Temporarily Restricted Net Assets**

Temporarily restricted net assets represent amounts received or committed with donor restrictions which have not yet been expended for their designated purpose (purpose restricted) or amounts for use in future periods (time restricted). As of December 31, 2013, all amounts included in temporarily restricted net assets were purpose restricted.

#### Revenue Recognition

NORD reports gifts and grants of cash and other assets as temporarily restricted revenue and net assets, if they are received or unconditionally committed with donor stipulations that limit the use of the asset. When a donor restriction expires, that is, when a stipulated time restriction ends or 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. Revenue from unrestricted grants and contributions is recorded when received or committed.

Patient assistance and research program fees revenue is recorded as services are provided and revenue is earned. Royalty income is recorded annually in accordance with a contract agreement from publication of certain curricula and software developed by NORD. Special events revenue is recognized in the year the event occurs. Membership revenue is recorded when earned at the beginning of the year the membership is effective. All other revenue is recorded when earned.

NORD is and may be named beneficiary of trusts and wills. The amounts to be received, if any, cannot be determined and are therefore not reflected in the accompanying financial statements until received. During 2013, NORD received bequests of \$18,029 which are included contributions and bequests in the accompanying statement of activities.

#### NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2013

(Continued)

# (1) <u>OPERATIONS, NONPROFIT STATUS AND SIGNIFICANT ACCOUNTING POLICIES</u> (Continued)

#### **SIGNIFICANT ACCOUNTING POLICIES (Continued)**

#### Marketing and Advertising Costs

NORD expenses marketing and advertising costs as they are incurred.

#### **Expense Allocation**

Expenses related directly to a program are allocated to that program, while other expenses are allocated based upon management's estimate of the percentage attributable to each program.

#### **Estimates**

The preparation of financial statements in accordance with U.S. GAAP requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

#### **Income Taxes**

NORD accounts for uncertainty in income taxes in accordance with ASC Topic, *Income Taxes*. This standard clarifies the accounting for uncertainty in tax positions and prescribes a recognition threshold and measurement attribute for the financial statement regarding a tax position taken or expected to be taken in a tax return. NORD has determined that there are no uncertain tax positions which qualify for either recognition or disclosure in the financial statements at December 31, 2013. NORD's information returns are subject to examination by Federal and state jurisdictions and generally remain open for the most recent three years.

#### **Subsequent Events**

Subsequent events have been evaluated through May 9, 2014, which is the date the financial statements were available to be issued.

#### (2) INVESTMENTS

Investments are presented in the accompanying financial statements at fair value using Level 1 inputs (see Note 1) and are comprised of fixed income mutual funds and donated stock as of December 31, 2013.

Investments are not insured and are subject to ongoing market fluctuations. Investments have been classified as long-term in the accompanying statement of financial position based upon management's intent.

During 2013, NORD received donated stock with a market value of \$5,579. It is NORD's policy to sell donated stock within a three month period to maximize the donation. As of December 31, 2013, approximately \$500 of donated stock remained in the investment balance.

#### NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2013

(Continued)

#### (2) <u>INVESTMENTS</u> (Continued)

Net gain on investments consists of the following:

Realized gain on investments	\$17,363
Unrealized loss on investments	<u>(4,886)</u>
Net gain on investments	\$12,477

#### (3) PROPERTY AND EQUIPMENT

Net property and equipment consist of the following as of December 31, 2013:

Land	\$ 505,203
Furniture and fixtures	1,293,863
Building and improvements	767,812
Computers and computer software	334,735
Leasehold improvements	11,910
	2,913,523
Less - accumulated depreciation	1,266,225
Net property and equipment	\$1 647 298
rice property and equipment	$\frac{\psi_1,0+r,2}{2}$

#### (4) LONG-TERM DEBT

NORD has a mortgage note payable to a bank secured by property owned by NORD. Payments of principal and interest at 5.75% were due in 240 monthly installments of \$7,021 through February, 2024. In August, 2013, the remaining principal balance of \$666,768 was refinanced and the interest rate was reduced to 4.9%. Amended monthly principal and interest payments are \$6,739, which are due through February, 2024. The balance outstanding on the note was \$646,522 as of December 31, 2013.

The note agreement contains various covenants with which NORD must comply. At December 31, 2013, NORD was in compliance with the covenants.

The future principal payments over the next five fiscal years are as follows:

2014	\$50,309
2015	\$52,830
2016	\$55,478
2017	\$58,258
2018	\$61,178

#### (5) LEASE AGREEMENTS

NORD leases office space under operating leases in Massachusetts and Washington D.C., which expire in January, 2018 and April, 2019, respectively. The terms of these lease agreements are Five years and rents increase annually under both leases. The facility leases require NORD to maintain certain insurance coverage and pay for its proportionate share of real estate taxes and operating expenses, as defined in the agreement. Rent expense was \$209,519 for the year ended December 31, 2013, and is reflected as rent in the accompanying statement of functional expenses.

#### NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2013

(Continued)

#### (5) **LEASE AGREEMENTS** (Continued)

Future minimum lease payments under these agreements for the next five years are as follows:

2014	\$216,920
2015	\$220,032
2016	\$223,704
2017	\$226,764
2018	\$147,244

Both lease agreements contain renewal options, which have not been exercised.

#### (6) <u>EMPLOYMENT BENEFIT PLANS</u>

NORD has adopted a tax-deferred pension plan under Section 403(b) of the IRC for all employees. NORD contributes 5% of each participant's annual salary to the plan. NORD's contributions for the year ended December 31, 2013, totaled \$111,832, which is included in payroll taxes and fringe benefits in the accompanying statement of functional expenses.

#### (7) <u>CONCENTRATIONS</u>

NORD maintains its operating cash balances in various banks. The Federal Deposit Insurance Corporation (FDIC) insures balances at each bank up to certain amounts. At certain times during the year ended December 31, 2013, cash balances exceeded the insured amounts. NORD has not experienced any losses in such accounts. NORD believes it is not exposed to any significant credit risk on its operating cash balance.

Revenue and accounts receivable concentrations are comprised of the following private donors at December 31, 2013:

	Accounts <u>Receivable</u>	Revenue
Payor A	31%	2%
Payor B	17%	1%
Payor C	- %	27%
Payor D	- %	13%

#### (8) PRIOR PERIOD ADJUSTMENT

During fiscal year 2013, NORD discovered certain temporarily restricted net asset balances were not released even though the purpose restriction had been met. The effect of this misclassification resulted in a \$432,121 overstatement of temporarily restricted net assets and a \$432,121 understatement of unrestricted net assets. The net effect of this misclassification resulted in no misstatement of total net assets as of December 31, 2012.

# NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2013 (Continued)

#### **PRIOR PERIOD ADJUSTMENT** (Continued) **(8)**

Net assets as of December 31, 2012, have been restated as follows:

	Unrestricted	Temporarily Restricted	<u>Total</u>
Net assets, December 31, 2012, as previously stated	\$4,484,556	\$2,614,567	\$7,099,123
To correct misclassification	432,121	(432,121)	
Net assets, December 31, 2012, as restated	<u>\$4,916,677</u>	<u>\$2,182,446</u>	<u>\$7,099,123</u>