

FINANCIAL STATEMENTS DECEMBER 31, 2017 AND 2016

Contents December 31, 2017 and 2016

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50 Washington Street Westborough, MA 01581 508.366.9100 aafcpa.com

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 statements of financial position as of December 31, 2017 and 2016, and the related statements of unrestricted activities, changes in net assets 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 National Organization for Rare Disorders, 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.

lepander, Acouser, Finning & Co., P.C.

Westborough, Massachusetts May 8, 2018

Statements of Financial Position December 31, 2017 and 2016

Assets	2017	2016
Current Assets:		
Cash	\$ 26,821,292	\$ 9,426,549
Certificates of deposit	-	1,237,499
Accounts receivable, net of allowance for doubtful accounts of \$225,000 and \$255,000 at December 31, 2017 and 2016,		
respectively	9,325,035	10,806,349
Prepaid expenses	235,018	146,170
Total current assets	36,381,345	21,616,567
Investments - Deferred Compensation	85,000	-
Property, Equipment and Software, net	1,757,378	1,648,289
Software Under Development	56,040	
Total assets	\$ 38,279,763	\$ 23,264,856
Liabilities and Net Assets	_	
Current Liabilities:	\$ 61,178	ć горго
Current portion of long-term debt Accounts payable	\$	\$
Accrued expenses	390,915	361,848
Current portion of research grants payable	489,975	413,025
Deferred revenue	479,248	620,910
Total current liabilities	1,924,337	1,779,811
Deferred Compensation	85,000	-
Research Grants Payable, net of current portion	239,600	533,430
Long-Term Debt, net of current portion	368,467	429,645
Total liabilities	2,617,404	2,742,886
Net Assets:		
Unrestricted:		
Operating	2,037,441	2,442,470
Property, equipment and software and		
software under development	1,383,773	1,160,386
Total unrestricted	3,421,214	3,602,856
Temporarily restricted	32,241,145	16,919,114
Total net assets	35,662,359	20,521,970
Total liabilities and net assets	\$ 38,279,763	\$ 23,264,856

The accompanying notes are an integral part of these statements.

Statements of Unrestricted Activities For the Years Ended December 31, 2017 and 2016

	2017	2016
Changes in Unrestricted Net Assets:		
Patient services:		
Patient service program funds	\$ 734,214	\$ 1,156,718
Net assets released from purpose restrictions	24,433,413	19,126,809
Patient service expense	(25,001,768)	(20,418,421)
Net patient service revenue (expense)	165,859	(134,894)
Research grants:		
Net assets released from purpose restrictions	109,794	339,200
Research grant expense	(109,794)	(339,200)
Net research grants		
Other revenue and support:		
Patient assistance and research program fees	3,461,133	3,240,451
Special events revenue	1,856,417	1,110,540
Membership dues	1,321,624	1,310,303
Contributions and bequests	1,241,546	1,146,562
Registry, web subscriptions and other related fees	158,076	296,822
Interest and dividend income	21,741	18,086
Federal grants	-	187,500
Net assets released from purpose restrictions - contributions	242,246	59,052
Total other revenue and support	8,302,783	7,369,316
Total unrestricted revenue and support	8,468,642	7,234,422
Other expenses:		
Personnel and related	5,387,231	4,976,397
Conferences, meetings and travel	1,184,395	604,838
Other	1,050,490	768,974
Occupancy	538,867	538,269
Bad debt	291,607	320,700
Depreciation	197,694	980,649
Total other expenses	8,650,284	8,189,827
Changes in unrestricted net assets	\$ (181,642)	\$ (955,405)

Statements of Changes in Net Assets For the Years Ended December 31, 2017 and 2016

	Unrestricted	Temporarily Restricted Research			Total	
		Patient Service	Grants	Other	Total	
Net Assets, December 31, 2015	\$ 4,558,261	\$ 5,540,885	\$ 454,935	\$ 430,158	\$ 6,425,978	\$ 10,984,239
Unrestricted revenue	8,466,982	-	-	-	-	8,466,982
Temporarily restricted grants and contributions	-	29,749,604	268,593	-	30,018,197	30,018,197
Net assets released from restrictions	19,525,061	(19,126,809)	(339,200)	(59,052)	(19,525,061)	-
Total expenses	(28,947,448)					(28,947,448)
Changes in net assets	(955,405)	10,622,795	(70,607)	(59,052)	10,493,136	9,537,731
Net Assets, December 31, 2016	3,602,856	16,163,680	384,328	371,106	16,919,114	20,521,970
Unrestricted revenue	8,794,751	-	-	-	-	8,794,751
Temporarily restricted grants and contributions	-	39,605,055	337,995	164,434	40,107,484	40,107,484
Net assets released from restrictions	24,785,453	(24,433,413)	(109,794)	(242,246)	(24,785,453)	-
Total expenses	(33,761,846)					(33,761,846)
Changes in net assets	(181,642)	15,171,642	228,201	(77,812)	15,322,031	15,140,389
Net Assets, December 31, 2017	\$ 3,421,214	\$ 31,335,322	\$ 612,529	\$ 293,294	\$ 32,241,145	\$ 35,662,359

Statements of Cash Flows For the Years Ended December 31, 2017 and 2016

	2017	2016
Cash Flows from Operating Activities:		
Changes in net assets	\$ 15,140,389	\$ 9,537,731
Adjustments to reconcile changes in net assets to net cash		
provided by operating activities:		
Depreciation	197,694	980,649
Bad debt	291,607	255,000
Loss on disposal of property, equipment and software	22,420	-
Net gain on investments	-	(5,099)
Donated investments	-	(139,887)
Changes in operating assets and liabilities:		
Accounts receivable	1,189,707	(8,796,041)
Prepaid expenses	(88,848)	(24,662)
Accounts payable	177,251	(319,142)
Accrued expenses	29,067	127,228
Research grants payable	(216,880)	53,703
Deferred compensation	85,000	-
Deferred revenue	(141,662)	169,310
Net cash provided by operating activities	16,685,745	1,838,790
Cash Flows from Investing Activities:		
Reinvested interest earned on certificates of deposit	-	(1,909)
Maturities of certificates of deposit	1,237,499	220,621
Proceeds from sales of investments	-	396,946
Purchase of investments - deferred compensation	(85,000)	-
Investment in software under development	(56,040)	-
Acquisition of property, equipment and software	(329,203)	(82,348)
Net cash provided by investing activities	767,256	533,310
Cash Flows from Financing Activities:		
Principal payments on long-term debt	(58,258)	(55,479)
Net Change in Cash	17,394,743	2,316,621
Cash:		
Beginning of year	9,426,549	7,109,928
End of year	\$ 26,821,292	\$ 9,426,549
Supplemental Disclosure of Cash Flow Information:		
Cash paid for interest	\$ 22,610	\$ 25,391
Supplemental Disclosure of Non-Cash Transactions:		
Software under development placed in service	\$ -	\$ 1,251,022

The accompanying notes are an integral part of these statements.

Notes to Financial Statements December 31, 2017 and 2016

1. 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 raised by NORD from grants and donations from foundations, corporations and individuals.

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.

2. 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 in these notes are to the FASB Accounting Standards Codification (ASC).

Accounts Receivable and Allowance for Doubtful Accounts

Accounts receivable at December 31, 2017 and 2016, consist mainly of amounts due in the next year for program grants. An allowance for doubtful accounts is based on collection experience and other circumstances which may affect the ability of NORD to collect. The allowance for doubtful accounts at December 31, 2017 and 2016, was \$225,000 and \$255,000, respectively.

Fair Value Measurements

NORD follows the accounting and disclosure standards pertaining to ASC Topic, *Fair Value Measurements*, for qualifying assets and liabilities. Fair value is defined as the price that NORD would receive upon selling an asset or pay to settle a liability in an orderly transaction between market participants.

NORD uses a framework for measuring fair value that includes a hierarchy that categorizes and prioritizes the sources used to measure and disclose fair value. This hierarchy is broken down into three levels based on inputs that market participants would use in valuing the financial instruments based on market data obtained from sources independent of NORD. Inputs refer broadly to the assumptions that market participants would use in pricing the financial instrument, including assumptions about risk. Inputs may be observable or unobservable. Observable inputs are inputs that reflect the assumptions market participants would use in pricing the financial instrument developed based on market data obtained from sources independent of the reporting entity. Unobservable inputs are inputs that reflect the reporting entity's own assumptions about the assumptions market participants would use in pricing the asset developed based on the best information available.

Notes to Financial Statements December 31, 2017 and 2016

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Fair Value Measurements (Continued)

The three-tier hierarchy of inputs is summarized in the three broad levels 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 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 and which require significant judgment or estimation.

An 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.

Certificates of Deposit

The certificates of deposit matured at various dates through March 2017. The certificates of deposit earned interest at rates ranging from .15% to .5% during 2017 and 2016. Certificates of deposit were measured at fair value using Level 1 inputs within the fair value hierarchy.

All Other Assets and Liabilities

The carrying value of all other qualifying assets and liabilities does not differ materially from its estimated fair value and are considered Level 1 in the fair value hierarchy.

Property, Equipment and Software and Depreciation

Property, equipment and software are recorded at cost when purchased or developed 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:

	Estimated <u>Useful Lives</u>
Building and improvements	5 - 20 years
Furniture and fixtures	5 - 10 years
Computers and computer software	3 - 5 years

Software Under Development

Software under development includes the cost of routine updates to software placed in service in the prior year and these updates will be released in 2018. The cost related to software or modules not placed in service as of December 31, 2017, was \$56,040 and is reflected as software under development in the accompanying statement of financial position.

Notes to Financial Statements December 31, 2017 and 2016

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Research Grants Payable

Research grants are recorded when awarded by NORD. Payments are made when certain milestones are met by the researchers. The final payment is made when the research is considered substantially completed. Research grants expected to be paid during the subsequent fiscal year are shown as current liabilities in the accompanying statements of financial position. Non-current research grants payable are expected to be paid in 2019.

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 - Represents 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 that have not yet been expended for their designated purpose (purpose restricted) or amounts for use in future periods (time restricted). As of December 31, 2017 and 2016, 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 statements of unrestricted 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, and patient service program funds are recorded as services are provided and revenue is earned. Registry and web subscriptions are recorded annually in accordance with contract agreements. Special events revenue is recognized in the year the event occurs. Membership dues revenue is recorded when earned at the beginning of the year the membership is effective. All other revenue is recorded when earned. Deferred revenue consists of membership revenue received in advance of the membership effective date and funding advances which will be recognized as revenue when the services are provided.

NORD is and may be named beneficiary of trusts and wills. The amounts to be received, if any, cannot always be determined and are therefore not reflected in the accompanying financial statements because the donors' wills have not yet been declared valid by the probate court, and the value of the amounts to be received is not yet determinable. NORD received bequests of \$53,316 and \$146,018 for the years ended December 31, 2017 and 2016, respectively, which are included in contributions and bequests in the accompanying statements of unrestricted activities.

Notes to Financial Statements December 31, 2017 and 2016

2. 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 function, while other expenses are allocated based upon management's estimate of the percentage attributable to each function. Expense allocation by function and classification is as follows for the years ended December 31:

	2017			
	Program	General and <u>Administrative</u>	Development and <u>Communication</u>	Total
Patient service expense	\$ 25,001,768	\$-	\$-	\$ 25,001,768
Research grant expense	109,794	-	-	109,794
Personnel and related	2,492,805	2,046,613	847,813	5,387,231
Conferences, meetings				
and travel	352,643	98,955	732,797	1,184,395
Other	210,493	488,370	351,627	1,050,490
Occupancy	9,252	526,450	3,165	538,867
Bad debt	-	291,607	-	291,607
Depreciation	125,007	70,221	2,466	197,694
Total	<u>\$ 28,301,762</u>	<u>\$ 3,522,216</u>	<u>\$ 1,937,868</u>	<u>\$ 33,761,846</u>

	2016			
	Program	General and Administrative	Development and <u>Communication</u>	Total
Patient service expense	\$ 20,418,421	\$-	\$-	\$ 20,418,421
Research grant expense	339,200	-	-	339,200
Personnel and related	1,960,386	2,318,848	697,163	4,976,397
Conferences, meetings				
and travel	245,349	100,846	258,643	604,838
Other	307,385	300,980	160,609	768,974
Occupancy	187,854	332,621	17,794	538,269
Bad debt	-	320,700	-	320,700
Depreciation	819,877	160,772		980,649
Total	<u>\$ 24,278,472</u>	<u>\$ 3,534,767</u>	<u>\$ 1,134,209</u>	<u>\$ 28,947,448</u>

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.

Notes to Financial Statements December 31, 2017 and 2016

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Change in Accounting Estimate

NORD reviews the estimated useful lives of its property, equipment and software on an ongoing basis, and this review indicated that the actual life of certain software was longer than estimates previously used. Effective January 2017, NORD changed its estimate of the useful life of the affected software to better reflect the estimated periods the asset will remain in service. The estimated useful life of affected software was increased from three to five years. The effect of this change in estimate reduced 2017 depreciation expense by approximately \$213,000.

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 statements 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, 2017 and 2016. NORD's information returns are subject to examination by the Federal and state jurisdictions.

Subsequent Events

Subsequent events have been evaluated through May 8, 2018, which is the date the financial statements were available to be issued. There were no events that met the criteria for recognition or disclosure in the financial statements.

3. PROPERTY, EQUIPMENT AND SOFTWARE

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

	2017	2016
Land Building and improvements	\$ 505,203 792,462	\$ 505,203 767,812
Computers and computer software Furniture and fixtures	2,043,807 21,656	1,653,538 <u>1,008,541</u>
Less - accumulated depreciation	3,363,128 <u>1,605,750</u>	3,935,094 2,286,805
Net property, equipment and software	<u>\$ 1,757,378</u>	<u>\$ 1,648,289</u>

4. LONG-TERM DEBT

NORD has a mortgage note payable to a bank which is secured by certain property. Payments of principal and interest at 4.9% are due in monthly installments of \$6,739 through February 2024, the note's maturity. Interest paid on the note was \$22,610 and \$25,391 for the years ended December 31, 2017 and 2016, respectively, which is included in other in the accompanying statements of unrestricted activities. The balance outstanding on the note was \$429,645 and \$487,903 as of December 31, 2017 and 2016, respectively.

The note agreement contains various covenants with which NORD must comply. At December 31, 2017 and 2016, NORD was in compliance with the covenants.

4. LONG-TERM DEBT (Continued)

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

2018	\$ 61,178
2019	\$ 64,244
2020	\$ 67,464
2021	\$ 70,845
2022	\$ 74,395

5. LEASE AGREEMENTS

NORD leases office space under operating leases in Massachusetts and Washington D.C., which expire in June 2022 and April 2019, respectively. Monthly payments under the terms of the agreements ranged from \$6,093 to \$8,820 during 2017 and 2016. In future years, payments range from \$6,093 to \$10,440. 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 agreements. Rent expense was \$243,079 and \$229,084 for the years ended December 31, 2017 and 2016, respectively, which is included in occupancy in the accompanying statements of unrestricted activities. One of the facility leases is recorded on the straight-line method over the lease term. The rent accrued in excess of the rent paid, approximately \$28,000, is included in accrued expenses in the accompanying statement of financial position for the year ended December 31, 2017.

Future minimum base lease payments under these agreements are as follows:

2018	\$ 180,571
2019	\$ 135,610
2020	\$ 115,560
2021	\$ 119,880
2022	\$ 61,560

Both lease agreements contain renewal options.

6. EMPLOYMENT BENEFIT PLANS

NORD maintains a tax-deferred pension plan under Section 403(b) of the IRC. Employees may contribute to the plan, however, employer contributions are not allowable under the plan.

NORD also maintains a defined contribution pension plan under Section 401(a) of the IRC. NORD contributes 5% of each participant's annual salary into the plan. NORD's contributions for the years ended December 31, 2017 and 2016, totaled \$187,300 and \$143,881, respectively, which is included in personnel and related in the accompanying statements of unrestricted activities.

Beginning in 2017, NORD maintains deferred compensation plans for certain members of its senior management team. NORD makes annual discretionary contributions to these plans as determined by the Board of Directors. The total amount accrued for these plans as of December 31, 2017, is \$85,000, which is included in investment - deferred compensation and deferred compensation liability in the accompanying statements of financial position. The liability is classified as long-term since NORD intends to pay the balances to certain retired employees in accordance with the plans. These employees will receive payments upon retirement, which is expected to be more than one year from the statement of financial position date. NORD's contribution expense under this plan was \$85,000 for the year ended December 31, 2017, which is included in personnel and related in the accompanying statement of unrestricted activities.

Notes to Financial Statements December 31, 2017 and 2016

7. CONCENTRATIONS

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 years ended December 31, 2017 and 2016, 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.

Accounts receivable and revenue and support concentrations are comprised of the following private donors at December 31:

	2(017	2	016
Donor	Percentage of Accounts <u>Receivable</u>	Percentage of Revenue	Percentage of Accounts <u>Receivable</u>	Percentage of Revenue
А	- %	24%	- %	28%
В	- %	12%	- %	- %
С	60%	11%	46%	23%
D	32%	10%	- %	- %
E	- %	- %	30%	15%

8. CONTINGENCY

In the ordinary course of NORD's business, NORD is from time-to-time involved in disputes concerning business and employment matters of NORD. While damages in connection with these disputes are possible, NORD denies any wrong doing in these cases and is taking the appropriate legal steps in defense of these disputes. It is management's opinion that any potential settlement would not be material to the accompanying financial statements.

9. UNEMPLOYMENT INSURANCE

NORD is self-insured for unemployment claims for one of its locations. NORD holds a prepaid account to fund the insurance through the Unemployment Services Trust. Claim liabilities are requested from the state through the Trust. As of December 31, 2017 and 2016, the balance in the prepaid unemployment insurance account was \$86,737 and \$55,476, respectively, which is included in prepaid expenses in the accompanying statements of financial position. The unemployment insurance account is available to fund future unemployment claims.

10. RECLASSIFICATIONS

Certain amounts in the fiscal year 2016 financial statements have been reclassified to conform with the 2017 presentation.