



**NORD**<sup>®</sup>

National Organization  
for Rare Disorders

**FINANCIAL STATEMENTS**  
**DECEMBER 31, 2018 AND 2017**

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

Contents  
December 31, 2018 and 2017

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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 statements of financial position as of December 31, 2018 and 2017, and the related statements of activities without donor restrictions, 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, 2018 and 2017, 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.

*Alexander, Brown, Pinning & Co., P.C.*

Westborough, Massachusetts  
November 7, 2019

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

Statements of Financial Position  
December 31, 2018 and 2017

| <b>Assets</b>  | <b>2018</b>          | <b>2017</b>          |
|--|----------------------|----------------------|
| Current Assets:  |                      |                      |
| Cash and cash equivalents  | \$ 45,972,783        | \$ 26,821,292        |
| Accounts receivable, net of allowance for doubtful accounts of \$210,000 and \$225,000 at December 31, 2018 and 2017, respectively | 2,687,602            | 9,325,035            |
| Prepaid expenses   | 316,998              | 235,018              |
| Total current assets   | 48,977,383           | 36,381,345           |
| Investments - Deferred Compensation  | 104,052              | 85,000               |
| Deferred Hosting Arrangement Costs   | 107,063              | 21,245               |
| Property, Equipment and Software, net  | 1,625,587            | 1,757,378            |
| Software Under Development   | 23,943               | 34,795               |
| Total assets   | <u>\$ 50,838,028</u> | <u>\$ 38,279,763</u> |
| <b>Liabilities and Net Assets</b>  |                      |                      |
| Current Liabilities:   |                      |                      |
| Current portion of long-term debt  | \$ 64,244            | \$ 61,177            |
| Accounts payable   | 401,268              | 503,021              |
| Accrued expenses   | 193,870              | 362,601              |
| Current portion of research grants payable   | 184,611              | 489,975              |
| Deferred revenue   | 585,652              | 507,562              |
| Total current liabilities  | 1,429,645            | 1,924,336            |
| Deferred Compensation  | 104,052              | 85,000               |
| Research Grants Payable, net of current portion  | 289,467              | 239,600              |
| Long-Term Debt, net of current portion   | 304,224              | 368,468              |
| Total liabilities  | <u>2,127,388</u>     | <u>2,617,404</u>     |
| Net Assets:  |                      |                      |
| Without donor restrictions:  |                      |                      |
| Operating  | 2,008,178            | 2,058,686            |
| Property, equipment and software and software under development  | 1,281,062            | 1,362,528            |
| Total without donor restrictions   | 3,289,240            | 3,421,214            |
| With donor restrictions  | 45,421,400           | 32,241,145           |
| Total net assets   | <u>48,710,640</u>    | <u>35,662,359</u>    |
| Total liabilities and net assets   | <u>\$ 50,838,028</u> | <u>\$ 38,279,763</u> |

**NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.**Statements of Activities Without Donor Restrictions  
For the Years Ended December 31, 2018 and 2017

|   | <u>2018</u>         | <u>2017</u>         |
|---|---------------------|---------------------|
| <b>Changes in Net Assets Without Donor Restrictions:</b>      |                     |                     |
| Patient services:   |                     |                     |
| Patient service program funds                                 | \$ 599,170          | \$ 734,214          |
| Net assets released from purpose restrictions                 | 25,466,847          | 24,433,413          |
| Patient service expense                                       | <u>(25,639,741)</u> | <u>(25,001,768)</u> |
| Patient service revenue, net                                  | <u>426,276</u>      | <u>165,859</u>      |
| Research grants:  |                     |                     |
| Net assets released from purpose restrictions                 | -                   | 109,794             |
| Research grant expense  | <u>-</u>            | <u>(109,794)</u>    |
| Research grants, net  | <u>-</u>            | <u>-</u>            |
| Other revenue and support:                                    |                     |                     |
| Patient assistance and research program fees                  | 3,865,614           | 3,461,133           |
| Special events revenue  | 1,921,302           | 1,856,417           |
| Membership dues   | 1,329,569           | 1,321,624           |
| Contributions and bequests                                    | 787,535             | 1,241,546           |
| Interest and dividend income                                  | 145,033             | 21,741              |
| Registry, web subscriptions and other related fees            | 130,012             | 158,076             |
| Net assets released from purpose restrictions - contributions | <u>488,725</u>      | <u>242,246</u>      |
| Total other revenue and support                               | <u>8,667,790</u>    | <u>8,302,783</u>    |
| Other expenses:   |                     |                     |
| Personnel and related   | 5,678,800           | 5,387,231           |
| Conferences, meetings and travel                              | 1,068,069           | 1,184,395           |
| Professional fees   | 826,213             | 667,544             |
| Depreciation  | 620,970             | 197,694             |
| Occupancy   | 538,650             | 538,867             |
| Other   | 263,973             | 263,362             |
| Data systems and equipment                                    | 190,344             | 119,584             |
| Bad debt  | <u>39,021</u>       | <u>291,607</u>      |
| Total other expenses  | <u>9,226,040</u>    | <u>8,650,284</u>    |
| Changes in net assets without donor restrictions              | <u>\$ (131,974)</u> | <u>\$ (181,642)</u> |

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

Statements of Changes in Net Assets  
For the Years Ended December 31, 2018 and 2017

|  | <u>Without<br/>Donor<br/>Restrictions</u> | <u>With Donor Restrictions</u> |                            |                   | <u>Total</u>         |                      |
|--|---|--------------------------------|----------------------------|-------------------|----------------------|----------------------|
|  |   | <u>Patient Service</u>         | <u>Research<br/>Grants</u> | <u>Other</u>      |                      | <u>Total</u>         |
| <b>Net Assets, December 31, 2016</b>             | <u>\$ 3,602,856</u>                       | <u>\$ 16,163,680</u>           | <u>\$ 384,328</u>          | <u>\$ 371,106</u> | <u>\$ 16,919,114</u> | <u>\$ 20,521,970</u> |
| Revenue without donor restrictions               | 8,794,751                                 | -                              | -                          | -                 | -                    | 8,794,751            |
| Grants and contributions with donor restrictions | -   | 39,605,055                     | 337,995                    | 164,434           | 40,107,484           | 40,107,484           |
| Net assets released from donor restrictions      | 24,785,453                                | (24,433,413)                   | (109,794)                  | (242,246)         | (24,785,453)         | -                    |
| Total expenses                                   | <u>(33,761,846)</u>                       | <u>-</u>                       | <u>-</u>                   | <u>-</u>          | <u>-</u>             | <u>(33,761,846)</u>  |
| Changes in net assets                            | <u>(181,642)</u>                          | <u>15,171,642</u>              | <u>228,201</u>             | <u>(77,812)</u>   | <u>15,322,031</u>    | <u>15,140,389</u>    |
| <b>Net Assets, December 31, 2017</b>             | <u>3,421,214</u>                          | <u>31,335,322</u>              | <u>612,529</u>             | <u>293,294</u>    | <u>32,241,145</u>    | <u>35,662,359</u>    |
| Revenue without donor restrictions               | 8,778,235                                 | -                              | -                          | -                 | -                    | 8,778,235            |
| Grants and contributions with donor restrictions | -   | 37,447,173                     | 695,103                    | 993,551           | 39,135,827           | 39,135,827           |
| Net assets released from donor restrictions      | 25,955,572                                | (25,466,847)                   | -                          | (488,725)         | (25,955,572)         | -                    |
| Total expenses                                   | <u>(34,865,781)</u>                       | <u>-</u>                       | <u>-</u>                   | <u>-</u>          | <u>-</u>             | <u>(34,865,781)</u>  |
| Changes in net assets                            | <u>(131,974)</u>                          | <u>11,980,326</u>              | <u>695,103</u>             | <u>504,826</u>    | <u>13,180,255</u>    | <u>13,048,281</u>    |
| <b>Net Assets, December 31, 2018</b>             | <u>\$ 3,289,240</u>                       | <u>\$ 43,315,648</u>           | <u>\$ 1,307,632</u>        | <u>\$ 798,120</u> | <u>\$ 45,421,400</u> | <u>\$ 48,710,640</u> |

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

Statements of Cash Flows

For the Years Ended December 31, 2018 and 2017

|  | <u>2018</u>          | <u>2017</u>          |
|--|----------------------|----------------------|
| <b>Cash Flows from Operating Activities:</b>   |                      |                      |
| Changes in net assets  | \$ 13,048,281        | \$ 15,140,389        |
| Adjustments to reconcile changes in net assets to net cash provided by operating activities: |                      |                      |
| Depreciation   | 620,970              | 197,694              |
| Bad debt   | 39,021               | 291,607              |
| Loss on disposal of property, equipment and software   | -                    | 22,420               |
| Donated investments  | 159,608              | -                    |
| Changes in operating assets and liabilities:   |                      |                      |
| Accounts receivable  | 6,598,412            | 1,189,707            |
| Prepaid expenses   | (81,980)             | (88,848)             |
| Deferred hosting arrangement costs   | (85,818)             | -                    |
| Accounts payable   | (101,753)            | 177,251              |
| Accrued expenses   | (168,731)            | 29,067               |
| Research grants payable  | (255,497)            | (216,880)            |
| Deferred revenue   | 78,090               | (141,662)            |
| Deferred compensation  | 19,052               | 85,000               |
|  | <u>19,869,655</u>    | <u>16,685,745</u>    |
| Net cash provided by operating activities  |                      |                      |
|  | <u>19,869,655</u>    | <u>16,685,745</u>    |
| <b>Cash Flows from Investing Activities:</b>   |                      |                      |
| Maturities of certificates of deposit  | -                    | 1,237,499            |
| Proceeds from sales of investments   | (159,608)            | -                    |
| Purchase of investments - deferred compensation  | (19,052)             | (85,000)             |
| Investment in software under development   | -                    | (56,040)             |
| Acquisition of property, equipment and software  | (478,327)            | (329,203)            |
|  | <u>(656,987)</u>     | <u>767,256</u>       |
| Net cash provided by (used in) investing activities  |                      |                      |
|  | <u>(656,987)</u>     | <u>767,256</u>       |
| <b>Cash Flows from Financing Activities:</b>   |                      |                      |
| Principal payments on long-term debt   | (61,177)             | (58,258)             |
|  | <u>(61,177)</u>      | <u>(58,258)</u>      |
| <b>Net Change in Cash and Cash Equivalents</b>   | 19,151,491           | 17,394,743           |
| <b>Cash and Cash Equivalents:</b>  |                      |                      |
| Beginning of year  | <u>26,821,292</u>    | <u>9,426,549</u>     |
| End of year  | <u>\$ 45,972,783</u> | <u>\$ 26,821,292</u> |
| <b>Supplemental Disclosure of Cash Flow Information:</b>                                     |                      |                      |
| Cash paid for interest   | <u>\$ 19,691</u>     | <u>\$ 22,610</u>     |
| <b>Supplemental Disclosure of Non-Cash Transactions:</b>                                     |                      |                      |
| Software under development placed in service   | <u>\$ 10,852</u>     | <u>\$ -</u>          |

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2018 and 2017

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### 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).

#### Recently Adopted Accounting Pronouncements

In 2018, NORD adopted FASB's Accounting Standards Update (ASU) 2016-14, *Not-for-Profit Entities (Topic 958): Presentation of Financial Statements of Not-for-Profit Entities*. This ASU addresses the complexity and understandability of net asset classification, deficiencies in information about liquidity and availability of resources, and the lack of consistency in the type of information provided about expenses and investment return. NORD has adjusted the presentation of these financial statements accordingly. The adoption of this ASU did not impact NORD's net asset classes, results of operations, or cash flows for the year ended December 31, 2018. This ASU has been applied retrospectively to all periods presented. As allowed by this ASU, NORD has elected to omit the disclosures about liquidity and availability of resources for the December 31, 2017 financial statements.

In 2018, NORD early adopted ASU 2018-15, *Intangibles - Goodwill and Other - Internal-Use Software (Subtopic 350-40): Customer's Accounting for Implementation Costs Incurred in a Cloud Computing Arrangement that is a Service Contract*. ASU 2018-15 provides guidance on the accounting for implementation costs incurred to implement a hosting arrangement service contract. ASU 2018-15 requires NORD to amortize implementation costs over the term of the associated hosting arrangement on a straight-line basis and present the amortization expense of the capitalized implementation costs in the same line item in the statement of activities as the fees associated with the hosting arrangement. ASU 2018-15 also requires NORD to present the capitalized implementation costs in the same line item in the statement of financial position that a prepayment of the fees for the associated hosting arrangement would be presented. This ASU has been applied retrospectively to all periods presented and, as a result, certain amounts in the fiscal year 2017 financial statements have been reclassified in accordance with ASU 2018-15.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2018 and 2017

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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### Recently Adopted Accounting Pronouncements (Continued)

For the year ended December 31, 2018, hosting fees expense was \$12,272 which is included in data systems and equipment in the accompanying statements of activities without donor restrictions. There was no hosting fee expense for the year ended December 31, 2017. The unamortized hosting arrangement costs related to cloud computing arrangement service contracts are \$107,063 and \$21,275 as of December 31, 2018 and 2017, respectively.

#### Cash and Cash Equivalents

For the purpose of the statements of cash flows, management considers all highly liquid investments with an initial maturity of three months or less to be cash and cash equivalents. These funds include investments with maturities of less than one year, overnight bank deposits, and other short-term highly liquid debt securities.

#### Accounts Receivable and Allowance for Doubtful Accounts

Accounts receivable at December 31, 2018 and 2017, 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 NORDD to collect. The allowance for doubtful accounts at December 31, 2018 and 2017, was \$210,000 and \$225,000, respectively.

#### Fair Value Measurements

NORDD 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 NORDD would receive upon selling an asset or pay to settle a liability in an orderly transaction between market participants.

NORDD 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 NORDD. 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.

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. All qualifying assets and liabilities are valued using Level 1 inputs.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2018 and 2017

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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### Deferred Hosting Arrangement Costs

Implementation costs, including set up and other upfront fees, that are incurred to implement a hosting arrangement service contract are capitalized. Deferred hosting arrangement costs are expensed over the term of the hosting arrangements, including any reasonably certain renewal periods. Deferred hosting arrangement costs as of December 31, 2018, include unamortized implementation costs related to NORD's general ledger and development software. The deferred hosting arrangement costs are expected to be amortized through December 2021.

#### 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:

|                                 | <b><u>Estimated<br/>Useful Lives</u></b> |
|---------------------------------|--|
| 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 to advance and update NORD's proprietary software. The cost related to software or modules not placed in service as of December 31, 2018 and 2017, was \$23,943 and \$34,795, respectively, and is reflected as software under development in the accompanying statements of financial position. When the software update or advance is implemented, it is placed in service, depreciated and the asset is transferred to property, equipment and software in the accompanying statements of financial position.

#### 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 2020 or beyond.

#### 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, 2018 and 2017. NORD's information and tax returns are subject to examination by the Federal and state jurisdictions.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2018 and 2017

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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### Net Assets

##### *Net Assets Without Donor Restrictions*

Net assets without donor restrictions are those net resources that bear no external restrictions and are generally available for use by NORD. NORD has grouped its net assets without donor restrictions into the following categories:

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

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

##### *Net Assets With Donor Restrictions*

Net assets with donor restrictions 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, 2018 and 2017, net assets with donor restrictions are restricted for the following:

|                    | <u>2018</u>          | <u>2017</u>          |
|--------------------|----------------------|----------------------|
| Purpose restricted | \$ 44,371,400        | \$ 32,241,145        |
| Time restricted    | <u>1,050,000</u>     | <u>-</u>             |
| Total              | <u>\$ 45,421,400</u> | <u>\$ 32,241,145</u> |

#### Revenue Recognition

NORD reports gifts and grants of cash and other assets as revenue and net assets with donor restrictions 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, net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statements of activities without donor restrictions as net assets released from restrictions. Revenue from grants and contributions without donor restrictions 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 \$51,826 and \$53,316 for the years ended December 31, 2018 and 2017, respectively, which are included in contributions and bequests in the accompanying statements of activities without donor restrictions or as grants and contributions with donor restrictions in the accompanying statement of changes in net assets.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2018 and 2017

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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### Marketing and Advertising Costs

NORD expenses marketing and advertising costs as they are incurred.

#### 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.

#### 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.

#### Expense Allocation

Certain expenses are incurred which support the work performed under more than one grant or contract. Such expenses are allocated among the various grants and contracts based upon management's calculation of the amount attributable to each grant or contract. Expenses incurred for specific grants or contracts are charged directly to the applicable project.

The financial statements contain certain categories of expenses that are attributable to program and supporting functions. Therefore, these expenses require allocation on a reasonable basis that is consistently applied. The expenses that are allocated include personnel and related, occupancy, and depreciation, which are allocated based on an estimation of time spent, head count and level of effort spent on NORD's program and supporting functions. Expense allocation by function and classification is as follows for the years ended December 31:

|                                     | <b>2018</b>          |   |  |                      |
|-------------------------------------|----------------------|---|--|----------------------|
|                                     |                      | <b>Supporting Services</b>                  |  |                      |
|                                     | <b>Program</b>       | <b>General and<br/>Adminis-<br/>trative</b> | <b>Development<br/>and<br/>Communication</b> | <b>Total</b>         |
| Patient service expense             | \$ 25,639,741        | \$ -  | \$ -   | \$ 25,639,741        |
| Personnel and related               | 3,188,363            | 1,424,054                                   | 1,066,383                                    | 5,678,800            |
| Conferences, meetings<br>and travel | 566,200              | 118,659                                     | 383,210                                      | 1,068,069            |
| Professional fees                   | 386,664              | 321,419                                     | 118,130                                      | 826,213              |
| Depreciation                        | 572,703              | 16,950                                      | 31,317                                       | 620,970              |
| Occupancy                           | 242,969              | 245,810                                     | 49,871                                       | 538,650              |
| Other                               | 87,830               | 112,206                                     | 63,937                                       | 263,973              |
| Data systems and<br>equipment       | 26,474               | 124,080                                     | 39,790                                       | 190,344              |
| Bad debt                            | 39,021               | -   | -  | 39,021               |
| Total                               | <u>\$ 30,749,965</u> | <u>\$ 2,363,178</u>                         | <u>\$ 1,752,638</u>                          | <u>\$ 34,865,781</u> |

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### Expense Allocation (Continued)

|                                  | 2017                 |                            |                               | Total                |
|----------------------------------|----------------------|----------------------------|-------------------------------|----------------------|
|                                  | Program              | General and Administrative | Development and Communication |                      |
| Patient service expense          | \$ 25,001,768        | \$ -                       | \$ -                          | \$ 25,001,768        |
| 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            |
| Professional fees                | 119,087              | 297,880                    | 250,577                       | 667,544              |
| Depreciation                     | 172,766              | 10,563                     | 14,365                        | 197,694              |
| Occupancy                        | 151,890              | 355,480                    | 31,497                        | 538,867              |
| Other                            | 68,875               | 122,193                    | 72,294                        | 263,362              |
| Data systems                     | 114                  | 108,942                    | 10,528                        | 119,584              |
| Bad debt                         | 291,607              | -                          | -                             | 291,607              |
| Research grant expense           | 109,794              | -                          | -                             | 109,794              |
| Total                            | <u>\$ 28,761,349</u> | <u>\$ 3,040,626</u>        | <u>\$ 1,959,871</u>           | <u>\$ 33,761,846</u> |

#### Subsequent Events

Subsequent events have been evaluated through November 7, 2019, which is the date the financial statements were available to be issued. Except as disclosed in Note 4, 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 consisted of the following as of December 31:

|                                      | 2018                | 2017                |
|--------------------------------------|---------------------|---------------------|
| Land                                 | \$ 505,203          | \$ 505,203          |
| Building and improvements            | 800,387             | 792,462             |
| Computers and computer software      | 2,525,061           | 2,043,807           |
| Furniture and fixtures               | 21,656              | 21,656              |
|                                      | <u>3,852,307</u>    | <u>3,363,128</u>    |
| Less - accumulated depreciation      | <u>2,226,720</u>    | <u>1,605,750</u>    |
| Net property, equipment and software | <u>\$ 1,625,587</u> | <u>\$ 1,757,378</u> |

### 4. LONG-TERM DEBT

NORD has a mortgage note payable to a bank that 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 \$19,691 and \$22,610 for the years ended December 31, 2018 and 2017, respectively, which is included in other in the accompanying statements of activities without donor restrictions. The balance outstanding on the note was \$368,468 and \$429,645 as of December 31, 2018 and 2017, respectively.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
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### 4. LONG-TERM DEBT (Continued)

The note agreement contains various covenants with which NORD must comply. At December 31, 2018 and 2017, NORD was in compliance with the covenants.

The future principal payments are as follows:

|            |           |
|------------|-----------|
| 2019       | \$ 64,244 |
| 2020       | \$ 67,464 |
| 2021       | \$ 70,845 |
| 2022       | \$ 74,395 |
| 2023       | \$ 78,123 |
| Thereafter | \$ 13,397 |

Subsequent to year-end, NORD entered into a line of credit with a bank which allows for borrowings up to \$750,000 and is renewable annually by the bank commencing January 31, 2020. Borrowings under the agreement are due no later than the expiration date and interest is payable monthly at the LIBOR Daily Floating Rate plus 2.5%. The line of credit is secured by NORD's property. There were no amounts drawn on the line of credit subsequent to year-end.

### 5. LEASE AGREEMENTS

NORD leases office space under operating leases in Massachusetts and Washington D.C., which expire in June 2022 and April 2024, respectively. Monthly payments under the terms of the agreements ranged from \$6,093 to \$9,000 during 2018 and 2017. 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 \$246,742 and \$243,079 for the years ended December 31, 2018 and 2017, respectively, which is included in occupancy in the accompanying statements of activities without donor restrictions. 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 \$29,000 and \$28,000, is included in accrued expenses in the accompanying statements of financial position for the years ended December 31, 2018 and 2017, respectively.

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

|      |            |
|------|------------|
| 2019 | \$ 186,437 |
| 2020 | \$ 194,928 |
| 2021 | \$ 199,248 |
| 2022 | \$ 140,928 |
| 2023 | \$ 79,368  |

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, 2018 and 2017, totaled \$195,993 and \$187,300, respectively, which is included in personnel and related in the accompanying statements of activities without donor restrictions.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
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### 6. EMPLOYMENT BENEFIT PLANS (Continued)

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 amounts accrued for these plans as of December 31, 2018 and 2017, are \$104,052 and \$85,000, respectively, which are included in investment - deferred compensation and deferred compensation 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 the plans was \$19,052 and \$85,000 for the years ended December 31, 2018 and 2017, respectively, which is included in personnel and related in the accompanying statements of activities without donor restrictions.

### 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, 2018 and 2017, 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:

| Donor | 2018                              |   | 2017                              |   |
|-------|-----------------------------------|---|-----------------------------------|---|
|       | Percentage of Accounts Receivable | Percentage of Total Revenue and Support | Percentage of Accounts Receivable | Percentage of Total Revenue and Support |
| A     | - %                               | 21%                                     | - %                               | 24%                                     |
| B     | - %                               | 19%                                     | - %                               | 12%                                     |
| C     | - %                               | - %                                     | 60%                               | 11%                                     |
| D     | - %                               | - %                                     | 32%                               | 10%                                     |
| E     | 38%                               | - %                                     | - %                               | - %                                     |
| F     | 37%                               | - %                                     | - %                               | - %                                     |
| G     | 12%                               | - %                                     | - %                               | - %                                     |
| H     | - %                               | 14%                                     | - %                               | - %                                     |

### 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.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

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### 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, 2018 and 2017, the balance in the prepaid unemployment insurance account was \$121,060 and \$86,737, 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 2017 financial statements have been reclassified to conform with the 2018 presentation.

### 11. LIQUIDITY AND AVAILABILITY OF FINANCIAL ASSETS

NORD regularly monitors liquidity required to meet its operating needs and other contractual commitments, while also striving to maximize the investment of its available funds. NORD has various sources of liquidity at its disposal, including cash and cash equivalents and a line of credit in the amount of \$750,000. See Note 4 for information about NORD's line of credit.

For purposes of analyzing resources available to meet general expenditures over a 12-month period, NORD considers all expenditures related to its ongoing activities of its mission as well as the conduct of services undertaken to support those activities to be general expenditures. In addition to financial assets available to meet general expenditures over the next 12 months, NORD anticipates collecting sufficient revenue to cover general expenditures not covered by donor-restricted resources.

As of December 31, 2018, the total financial assets held by NORD that could readily be made available within one year of the statement of financial position date to meet general expenditures are as follows:

|   | <u>2018</u>         |
|---|---------------------|
| Cash and cash equivalents   | \$ 45,972,783       |
| Accounts receivable, net  | 2,687,602           |
| Less - amounts with donor-imposed restrictions  | <u>(44,371,400)</u> |
| Financial assets available to meet cash needs<br>for general expenditures within one year | <u>\$ 4,288,985</u> |