



**NORD**<sup>®</sup>

National Organization  
for Rare Disorders

**FINANCIAL STATEMENTS**  
**DECEMBER 31, 2019 AND 2018**

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

Contents  
December 31, 2019 and 2018

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	<u>Pages</u>
<b>Independent Auditor's Report</b> .....	1 - 1A
<b>Financial Statements:</b>	
Statements of Financial Position .....	2
Statements of Activities Without Donor Restrictions .....	3
Statements of Changes in Net Assets .....	4
Statements of Cash Flows .....	5
Notes to Financial Statements .....	6 - 15



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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, 2019 and 2018, 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, 2019 and 2018, 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.

***Emphasis of Matter***

As disclosed in Note 2 to the financial statements, during 2019, National Organization for Rare Disorders, Inc. adopted Accounting Standards Update (ASU) No. 2014-09, *Revenue from Contracts with Customers* (Topic 606) and ASU No. 2018-08, *Not-For-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made*. Our report is not modified with respect to that matter.

*AAFCPA, Inc.*

Westborough, Massachusetts  
June 30, 2020

**NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.**Statements of Financial Position  
December 31, 2019 and 2018

<b>Assets</b>	<b>2019</b>	<b>2018</b> <b>(As Adjusted)</b>
Current Assets:		
Cash and cash equivalents	\$ 47,708,054	\$ 45,972,783
Accounts receivable, net of allowance for doubtful accounts of \$225,000 and \$210,000 at December 31, 2019 and 2018, respectively	11,775,250	2,687,602
Prepaid expenses	353,136	316,998
Total current assets	59,836,440	48,977,383
Investments - Deferred Compensation	136,831	104,052
Deferred Hosting Arrangement Costs	189,191	107,063
Property, Equipment and Software, net	1,487,761	1,625,587
Software Under Development	100,873	23,943
Total assets	\$ 61,751,096	\$ 50,838,028
<b>Liabilities and Net Assets</b>		
Current Liabilities:		
Current portion of long-term debt	\$ 67,463	\$ 64,244
Accounts payable	660,712	401,268
Accrued expenses	260,474	193,870
Current portion of research grants payable	481,474	184,611
Deferred revenue	223,059	500,652
Total current liabilities	1,693,182	1,344,645
Deferred Compensation	136,831	104,052
Research Grants Payable, net of current portion	265,000	289,467
Long-Term Debt, net of current portion	236,760	304,224
Total liabilities	2,331,773	2,042,388
Net Assets:		
Without donor restrictions:		
Operating	3,830,508	2,008,178
Property, equipment and software and software under development	1,210,812	1,281,062
Total without donor restrictions	5,041,320	3,289,240
With donor restrictions	54,378,003	45,506,400
Total net assets	59,419,323	48,795,640
Total liabilities and net assets	\$ 61,751,096	\$ 50,838,028

The accompanying notes are an integral part of these statements.

Page 2

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

Statements of Activities Without Donor Restrictions  
For the Years Ended December 31, 2019 and 2018

	<u>2019</u>	<u>2018</u> <u>(As Adjusted)</u>
<b>Changes in Net Assets Without Donor Restrictions:</b>		
Patient services:		
Program fees	\$ 639,674	\$ 599,170
Net assets released from purpose restrictions	30,173,232	25,406,615
Patient assistance and reimbursement expense	<u>(30,812,906)</u>	<u>(25,639,741)</u>
Patient service revenue, net	<u>-</u>	<u>366,044</u>
Research grants:		
Net assets released from purpose restrictions	535,130	-
Research grant expense	<u>(535,130)</u>	<u>-</u>
Research grants, net	<u>-</u>	<u>-</u>
Other revenue and support:		
Special events revenue	2,405,019	1,921,302
Grants, contributions and bequests	1,111,020	748,514
Interest and dividend income	595,629	145,033
Registry, web subscriptions and other related fees	234,128	130,012
Drug, travel and lodging program administrative fees	174,162	214,161
Net assets released from purpose restrictions - patient service administrative fees	4,493,330	3,661,660
Net assets released from purpose restrictions - research grant administrative fees	34,020	-
Net assets released from time restrictions - membership dues	1,680,303	1,379,594
Net assets released from purpose restrictions - contributions	<u>1,775,409</u>	<u>488,725</u>
Total other revenue and support	<u>12,503,020</u>	<u>8,689,001</u>
Other expenses:		
Personnel and related	6,630,675	5,678,800
Conferences, meetings and travel	1,589,511	1,068,069
Professional fees	740,762	826,213
Depreciation	545,820	620,970
Occupancy	538,733	538,650
Other	376,844	263,973
Data systems and equipment	<u>328,595</u>	<u>190,344</u>
Total other expenses	<u>10,750,940</u>	<u>9,187,019</u>
Changes in net assets without donor restrictions	<u>\$ 1,752,080</u>	<u>\$ (131,974)</u>

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

Statements of Changes in Net Assets  
For the Years Ended December 31, 2019 and 2018

	Without Donor Restrictions	With Donor Restrictions				Total	Total
		Patient Service	Research Grants	Membership Dues	Other		
<b>Net Assets, December 31, 2017</b>	<u>\$ 3,421,214</u>	<u>\$ 31,335,322</u>	<u>\$ 612,529</u>	<u>\$ -</u>	<u>\$ 293,294</u>	<u>\$ 32,241,145</u>	<u>\$ 35,662,359</u>
Cumulative adjustment to adopt ASU 2014-09 and ASU 2018-08	<u>-</u>	<u>-</u>	<u>-</u>	<u>50,025</u>	<u>-</u>	<u>50,025</u>	<u>50,025</u>
<b>Net Assets, December 31, 2017, as adjusted</b>	<u>3,421,214</u>	<u>31,335,322</u>	<u>612,529</u>	<u>50,025</u>	<u>293,294</u>	<u>32,291,170</u>	<u>35,712,384</u>
Revenue without donor restrictions	3,758,192	-	-	-	-	-	3,758,192
Grants and contributions with donor restrictions	-	37,447,173	695,103	1,414,569	993,551	40,550,396	40,550,396
Net assets released from donor restrictions	30,936,594	(25,466,847)	-	(1,379,594)	(488,725)	(27,335,166)	3,601,428
Total expenses	<u>(34,826,760)</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(34,826,760)</u>
Changes in net assets	<u>(131,974)</u>	<u>11,980,326</u>	<u>695,103</u>	<u>34,975</u>	<u>504,826</u>	<u>13,215,230</u>	<u>13,083,256</u>
<b>Net Assets, December 31, 2018</b>	<u>3,289,240</u>	<u>43,315,648</u>	<u>1,307,632</u>	<u>85,000</u>	<u>798,120</u>	<u>45,506,400</u>	<u>48,795,640</u>
Revenue without donor restrictions	5,159,632	-	-	-	-	-	5,159,632
Grants and contributions with donor restrictions	-	43,657,500	576,127	1,665,303	1,664,097	47,563,027	47,563,027
Net assets released from donor restrictions	38,691,424	(34,666,562)	(569,150)	(1,680,303)	(1,775,409)	(38,691,424)	-
Transfers	-	242,307	-	-	(242,307)	-	-
Total expenses	<u>(42,098,976)</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(42,098,976)</u>
Changes in net assets	<u>1,752,080</u>	<u>9,233,245</u>	<u>6,977</u>	<u>(15,000)</u>	<u>(353,619)</u>	<u>8,871,603</u>	<u>10,623,683</u>
<b>Net Assets, December 31, 2019</b>	<u>\$ 5,041,320</u>	<u>\$ 52,548,893</u>	<u>\$ 1,314,609</u>	<u>\$ 70,000</u>	<u>\$ 444,501</u>	<u>\$ 54,378,003</u>	<u>\$ 59,419,323</u>

The accompanying notes are an integral part of these statements.

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

Statements of Cash Flows

For the Years Ended December 31, 2019 and 2018

	<u>2019</u>	<u>2018</u> (As Adjusted)
<b>Cash Flows from Operating Activities:</b>		
Changes in net assets	\$ 10,623,683	\$ 13,083,256
Adjustments to reconcile changes in net assets to net cash provided by operating activities:		
Depreciation	545,820	620,970
Bad debt	-	39,021
Donated investments	118,421	159,608
Changes in operating assets and liabilities:		
Accounts receivable	(9,087,648)	6,598,412
Prepaid expenses	(36,138)	(81,980)
Deferred hosting arrangement costs	(82,128)	(85,818)
Accounts payable	185,845	(101,753)
Accrued expenses	66,604	(168,731)
Research grants payable	272,396	(255,497)
Deferred revenue	(277,593)	43,115
Deferred compensation	32,779	19,052
	<u>2,362,041</u>	<u>19,869,655</u>
<b>Cash Flows from Investing Activities:</b>		
Proceeds from sales of investments	(118,421)	(159,608)
Purchase of investments - deferred compensation	(32,779)	(19,052)
Investment in software under development	(338,463)	-
Acquisition of property, equipment and software	(72,862)	(478,327)
	<u>(562,525)</u>	<u>(656,987)</u>
<b>Cash Flows from Financing Activities:</b>		
Principal payments on long-term debt	(64,245)	(61,177)
<b>Net Change in Cash and Cash Equivalents</b>	1,735,271	19,151,491
<b>Cash and Cash Equivalents:</b>		
Beginning of year	45,972,783	26,821,292
End of year	<u>\$ 47,708,054</u>	<u>\$ 45,972,783</u>
<b>Supplemental Disclosure of Cash Flow Information:</b>		
Cash paid for interest	<u>\$ 16,625</u>	<u>\$ 19,691</u>
<b>Supplemental Disclosure of Non-Cash Transactions:</b>		
Software under development placed in service	<u>\$ 335,132</u>	<u>\$ 10,852</u>
Software in development in accounts payable	<u>\$ 73,599</u>	<u>\$ -</u>

The accompanying notes are an integral part of these statements.



## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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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 Quincy, Massachusetts, with additional offices in Danbury, Connecticut 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).

#### Accounting Principle Adoptions

On January 1, 2019, NORD adopted FASB's Accounting Standards (ASU) 2014-09, *Revenue from Contracts with Customers (Topic 606)*, and ASU-2018-08, *Not-For-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made* using the full retrospective method. Accordingly, the 2018 financial statements have been adjusted using the newly adopted accounting standards. The adoption resulted in an increase in total net assets of \$50,025 as of January 1, 2018 due to changes in accounting treatment of membership dues (see below), and a reclassification of \$39,021 between revenue and expenses during 2018 due to the classification of expected uncollectable accounts as disclosed on page 7.

The core principle of Topic 606 is that an organization will recognize revenue when it transfers promised goods or services to customers in an amount that reflects the consideration to which the organization expects to be entitled in exchange for those goods or services. This standard also includes expanded disclosure requirements that result in an entity providing users of financial statements with comprehensive information about the nature, amount, timing, and uncertainty of revenue and cash flows arising from the organization's contracts with customers. This standard requires NORD to assess its revenue from contracts with customers, using a broadly defined five-step process.

Prior to adoption of Topic 606, membership dues were considered earned in a reciprocal transaction. Using the five-step process outlined in Topic 606, management has since determined membership dues do not qualify as reciprocal transactions as the exchange element is minimal and peripheral to the transaction. Membership dues for future periods were previously recorded as deferred revenue, and are now recorded under Topic 958 as a contribution restricted by the donor for future periods. For the remaining contracts with customers assessed, the timing and amount of revenue recognized previously is consistent with how revenue is recognized under Topic 606.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### Accounting Principle Adoptions (Continued)

Topic 958 clarifies and improves guidance for contributions received and contributions made and provides guidance to organizations on how to account for certain non-exchange transactions. In addition, it clarifies whether a contribution is conditional. As a result, it enhances comparability of financial information among not-for-profit entities. Based on NORD's evaluation of its grants, contributions, and bequests the timing and amount of revenue recognized previously is consistent with how revenue is recognized under Topic 958.

The following tables summarize the retrospective effects of adoption in 2018:

<u>Statements of Activities</u>	<u>2018 as Previously Reported</u>	<u>Effect of Adoption</u>	<u>2018 as Adjusted</u>
Net Assets, December 31, 2017	\$ 35,662,359	\$ -	\$ 35,662,359
Accumulative adjustment to adopt ASU 2014-09 and ASU 2018-08	<u>-</u>	<u>50,025</u>	<u>50,025</u>
Net assets, December 31, 2017, as adjusted	<u>35,662,359</u>	<u>50,025</u>	<u>35,712,384</u>
Revenue without donor restrictions and net assets released from donor restrictions	7,398,641	(39,021)	7,359,620
Grants and contributions with donor restrictions	40,550,396	-	40,550,396
Total expenses	<u>(34,865,781)</u>	<u>39,021</u>	<u>(34,826,760)</u>
Total changes in net assets	<u>13,083,256</u>	<u>-</u>	<u>13,083,256</u>
Net Assets, December 31, 2018	<u>\$ 48,745,615</u>	<u>\$ 50,025</u>	<u>\$ 48,795,640</u>

#### 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, overnight bank deposits, and other short-term highly liquid debt securities.

#### Accounts Receivable and Allowance for Doubtful Accounts

Accounts receivable at December 31, 2019 and 2018, includes approximately \$11,145,000 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, 2019 and 2018, was \$225,000 and \$210,000, respectively. Accounts receivable also includes contract service receivables of approximately \$631,000 representing unconditional rights to consideration and are considered receivables when the right to consideration is unconditional and only the passage of time is required before the payment of that consideration is due. Any estimated uncollectible amounts are generally considered implicit price concessions which directly reduce accounts receivable. Changes to the estimate of the transaction price are generally recorded as adjustments to revenue in the period of the change. Subsequent changes that are determined to be the result of an adverse change in the payer's ability to pay are recorded as bad debt expense.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### 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.

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.

#### 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, 2019 and 2018, include unamortized implementation costs related to NORD's budgeting and reporting software and development software. The deferred hosting arrangement costs are expected to be amortized through March 2022.

#### 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, 2019 and 2018, was \$100,873 and \$23,943, 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.

#### Marketing and Advertising Costs

NORD expenses marketing and advertising costs as they are incurred.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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### 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 2021 or beyond.

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

Land is not depreciated.

#### 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, 2019 and 2018, net assets with donor restrictions are restricted for the following:

	<b><u>2019</u></b>	<b><u>2018</u></b>
Purpose restricted	\$ 53,125,003	\$ 44,371,400
Time restricted	<u>1,253,000</u>	<u>1,135,000</u>
Total	<u>\$ 54,378,003</u>	<u>\$ 45,506,400</u>

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### Revenue Recognition

In accordance with Topic 958, NORO must determine whether a contribution (or a promise) is conditional or unconditional for transactions deemed to be a contribution. A contribution is considered to be a conditional contribution if an agreement includes a barrier that must be overcome and either a right of return of the assets or a right of release of a promise to transfer assets exists. Indicators of a barrier include a measurable barrier, a stipulation that limits discretion by the recipient on the conduct of an activity, and stipulations that are related to the purpose of the agreement. Topic 958 prescribes that NORO should not consider probability of compliance with the barrier when determining if such awards are conditional and should be reported as conditional grant advance liabilities until such conditions are met. NORO had no conditional grants at December 31, 2019 and 2018.

Drug, travel and lodging program fees and registry fees represent service revenue earned under contractual agreements with customers and is recorded as services are provided. Revenue is reported at the stated contract price with adjustments for any consideration for explicit and implicit price considerations. Advance payments on these fees are recorded as deferred revenue until contract obligations are met at which point they are recognized as revenue.

NORO 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 unconditionally committed by the donor.

Patient service program and administration fees are recorded as net assets with donor restrictions. When expense criteria are met, patient service program and administration fee revenue is recorded as net assets released from purpose restrictions under patient services on the statement of activities without donor restrictions. As there is no direct benefit received by the donor in this program, the transaction is not considered an exchange transaction required to be reported under Topic 606.

Research grant contributions are received and held as donor restricted contributions until a research grant award is given and are reclassified as net assets released from restrictions on the statement of activities without donor restrictions. Research grants administration fee revenue is withheld from the grant award and released from restriction upon award date and is considered peripheral to the research grant award transaction and are not considered an exchange transaction under Topic 606 as no direct benefit is received by the research grant funder.

Sponsorships, included in special events revenue on the statement of activities without donor restrictions, are recorded upon receipt and are recorded as net assets with donor restrictions. When expense criteria are met, revenue is recorded as net assets released from restrictions - contributions on the statement of activities without donor restrictions. As there is no direct benefit received by the sponsor, the transaction is not considered an exchange transaction required to be reported under Topic 606.

Membership dues, which are non-refundable, represent contributions restricted to the time period representing the membership period. The value of any membership services provided in exchange for membership rights are considered peripheral to the transaction. Membership dues are recorded as net assets with donor restrictions based upon the implied time restriction related to the effective membership period. Membership dues are reclassified to net assets without donor restrictions after time restrictions lapse and are reported in the statement of activities without donor restrictions as net assets released from time restrictions - membership dues.

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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### 2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

#### Revenue Recognition (Continued)

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 \$5,723 and \$50,557 for the years ended December 31, 2019 and 2018, respectively, which are included in grants, contributions and bequests in the accompanying statements of activities without donor restrictions. All other revenue is recorded when earned.

#### 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, 2019 and 2018. NORD's information returns are subject to examination by the Federal and state jurisdictions.

#### 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.

#### 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 occupancy and depreciation, which are allocated based on estimates of square footage occupied, as well as personnel and related, which are allocated based on an estimation of time spent, head count and level of effort spent on NORD's program and supporting functions.

#### Subsequent Events

Subsequent events have been evaluated through June 30, 2020, which is the date the financial statements were available to be issued. Except as disclosed in Note 13, there were no events that met the criteria for recognition or disclosure in the financial statements.

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

Notes to Financial Statements  
December 31, 2019 and 2018

**3. FUNCTIONAL EXPENSES**

Expense allocation by function and classification is as follows for the years ended December 31:

	<b>2019</b>			<b>Total</b>
	<b>Programs</b>	<b>Supporting Services</b>		
		<b>General and Adminis- trative</b>	<b>Development and Communication</b>	
Patient assistance and reimbursement	\$ 30,812,906	\$ -	\$ -	\$ 30,812,906
Personnel and related	3,441,946	2,135,039	1,053,690	6,630,675
Conferences, meetings and travel	1,122,833	142,277	324,401	1,589,511
Professional fees	437,613	242,471	60,678	740,762
Depreciation	509,778	21,811	14,231	545,820
Occupancy	284,649	173,268	80,816	538,733
Research grant expense	535,130	-	-	535,130
Other	235,162	50,206	91,476	376,844
Data systems and equipment	<u>81,781</u>	<u>163,025</u>	<u>83,789</u>	<u>328,595</u>
Total	<u>\$ 37,461,798</u>	<u>\$ 2,928,097</u>	<u>\$ 1,709,081</u>	<u>\$ 42,098,976</u>
	<b>2018</b>			<b>Total</b>
	<b>Programs</b>	<b>Supporting Services</b>		
		<b>General and Adminis- trative</b>	<b>Development and Communication</b>	
Patient assistance and reimbursement	\$ 25,639,741	\$ -	\$ -	\$ 25,639,741
Personnel and related	3,188,363	1,424,054	1,066,383	5,678,800
Conferences, meetings 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 equipment	<u>26,474</u>	<u>124,080</u>	<u>39,790</u>	<u>190,344</u>
Total	<u>\$ 30,710,944</u>	<u>\$ 2,363,178</u>	<u>\$ 1,752,638</u>	<u>\$ 34,826,760</u>

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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### 4. PROPERTY, EQUIPMENT AND SOFTWARE

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

	<u>2019</u>	<u>2018</u>
Land	\$ 505,203	\$ 505,203
Building and improvements	857,182	800,387
Computers and computer software	2,866,185	2,525,061
Furniture and fixtures	<u>31,731</u>	<u>21,656</u>
	4,260,301	3,852,307
Less - accumulated depreciation	<u>2,772,540</u>	<u>2,226,720</u>
Net property, equipment and software	<u>\$ 1,487,761</u>	<u>\$ 1,625,587</u>

### 5. LONG-TERM DEBT AND LINE OF CREDIT

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 \$16,625 and \$19,691 for the years ended December 31, 2019 and 2018, respectively, which is included in other in the accompanying statements of activities without donor restrictions. The balance outstanding on the note was \$304,223 and \$368,468 as of December 31, 2019 and 2018, respectively.

The note agreement contains various covenants with which NORD must comply. At December 31, 2019 and 2018, NORD was in compliance with the covenants.

The future principal payments are as follows:

2020	\$ 67,463
2021	\$ 70,845
2022	\$ 74,395
2023	\$ 78,123
2024	\$ 13,397

NORD has a line of credit with a bank which allows for borrowings up to \$750,000 and is renewable annually by the bank. The line of credit through May 31, 2020, was renewed subsequent to year end through May 31, 2021 (Note 13). 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. No amounts were drawn on the line of credit during 2019 or 2018.

### 6. 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 \$6,614 to \$6,093 during 2019 and 2018. In future years, payments range from \$6,614 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 \$255,691 and \$246,742 for the years ended December 31, 2019 and 2018, 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 \$26,000 and \$29,000, is included in accrued expenses in the accompanying statements of financial position for the years ended December 31, 2019 and 2018, respectively.



## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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### 6. LEASE AGREEMENTS (Continued)

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

2020	\$ 194,928
2021	\$ 199,248
2022	\$ 140,928
2023	\$ 79,368
2024	\$ 26,456

Both lease agreements contain renewal options.

### 7. 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, 2019 and 2018, totaled \$250,201 and \$195,993, respectively, which is included in personnel and related in the accompanying statements of activities without donor restrictions.

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, 2019 and 2018, are \$136,831 and \$104,052, 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 \$32,779 and \$19,052 for the years ended December 31, 2019 and 2018, respectively, which is included in personnel and related in the accompanying statements of activities without donor restrictions.

### 8. 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, 2019 and 2018, 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 cash and cash equivalents.

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

Donor	2019		2018	
	Percentage of Accounts Receivable	Percentage of Total Revenue and Support	Percentage of Accounts Receivable	Percentage of Total Revenue and Support
A	- %	20%	- %	21%
B	- %	- %	- %	19%
C	55%	16%	- %	9%
D	- %	- %	38%	- %
E	34%	2%	37%	3%
F	3%	16%	12%	1%
G	- %	13%	- %	14%

## NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements  
December 31, 2019 and 2018

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### 9. 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.

### 10. UNEMPLOYMENT INSURANCE

NORD is self-insured for unemployment claims for two of their locations. NORD holds a prepaid account to fund the insurance through the Unemployment Services Trust. Claim liabilities are requested from the states through the Trust. As of December 31, 2019 and 2018, the balance in the prepaid unemployment insurance account was \$124,579 and \$121,060, 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.

### 11. RECLASSIFICATIONS

Certain amounts in the 2018 financial statements have been reclassified to conform with the 2019 presentation.

### 12. 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 5 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, 2019 and 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>2019</u>	<u>2018</u>
Cash and cash equivalents	\$ 47,708,054	\$ 45,972,783
Accounts receivable, net	11,775,250	2,687,602
Less - amounts with donor-imposed restrictions	<u>(54,378,003)</u>	<u>(45,506,400)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 5,105,301</u>	<u>\$ 3,153,985</u>

### 13. SUBSEQUENT EVENTS

The COVID-19 pandemic in the United States has caused business disruption and a reduction in economic activity. While the disruption is currently expected to be temporary, there is considerable uncertainty around the duration and the impact it will have on NORD's operations and financial position. Any financial impact to NORD cannot be reasonably estimated at this time.

On May 27, 2020, NORD's line of credit was renewed through May 31, 2021 (see Note 5).