



**FINANCIAL STATEMENTS
DECEMBER 31, 2022 AND 2021**

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Contents
December 31, 2022 and 2021

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Independent Auditor's Report

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

Opinion

We have audited the financial statements of National Organization for Rare Disorders, Inc. (a New York nonprofit corporation) (NORD), which comprise the statements of financial position as of December 31, 2022 and 2021, and the related statements of activities and changes in net assets and cash flows for the years then ended, and the related notes to the financial statements.

In our opinion, the accompanying financial statements present fairly, in all material respects, the financial position of National Organization for Rare Disorders, Inc. as of December 31, 2022 and 2021, 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.

Basis for Opinion

We conducted our audits in accordance with auditing standards generally accepted in the United States of America (GAAS). Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of NORD and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audits. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Emphasis of a Matter

As disclosed in Note 2 to the financial statements, NORD has changed its method of accounting for leases in 2022 due to the adoption of Accounting Standards Update No. 2016-02, *Leases (Topic 842)*, effective January 1, 2022, using the modified retrospective approach. Our opinion is not modified with respect to that matter.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, which raise substantial doubt about NORD's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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 NORD's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, which raise substantial doubt about NORD's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

AAFCPA, Inc.

Westborough, Massachusetts
May 2, 2023

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Financial Position
December 31, 2022 and 2021

Assets	2022	2021
Current Assets:		
Cash and cash equivalents	\$ 7,189,095	\$ 13,488,659
Accounts, grants and contributions receivable, net of allowance for doubtful accounts of \$25,000 at December 31, 2022 and 2021	11,078,737	1,240,510
Prepaid expenses	232,983	351,001
Investments	28,046,028	20,808,366
Total current assets	<u>46,546,843</u>	<u>35,888,536</u>
Investments - Deferred Compensation	106,602	147,299
Investments - Endowment	201,076	244,364
Deferred Hosting Arrangement Costs	106,140	74,147
Operating Lease Right-of-Use Asset	421,247	-
Property, Equipment and Software, net	<u>2,160,212</u>	<u>1,520,900</u>
Total assets	<u><u>\$ 49,542,120</u></u>	<u><u>\$ 37,875,246</u></u>
Liabilities and Net Assets		
Current Liabilities:		
Current portion of long-term debt	\$ 77,294	\$ 74,640
Accounts payable and accrued expenses	1,421,641	1,435,985
Current portion of research grants payable	752,777	548,527
Operating lease liability - short-term	207,322	-
Deferred revenue	214,816	242,900
Total current liabilities	<u>2,673,850</u>	<u>2,302,052</u>
Research Grants Payable, net of current portion	218,875	393,758
Operating Lease Liability - Long-Term	224,323	-
Deferred Compensation	107,385	147,299
Long-Term Debt, net of current portion	<u>13,146</u>	<u>90,440</u>
Total liabilities	<u>3,237,579</u>	<u>2,933,549</u>
Net Assets:		
Without donor restrictions:		
Operating and board designated endowment	6,460,678	7,812,601
Property, equipment and software	2,059,374	1,355,820
Total without donor restrictions	<u>8,520,052</u>	<u>9,168,421</u>
With donor restrictions	<u>37,784,489</u>	<u>25,773,276</u>
Total net assets	<u>46,304,541</u>	<u>34,941,697</u>
Total liabilities and net assets	<u><u>\$ 49,542,120</u></u>	<u><u>\$ 37,875,246</u></u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Activities and Changes in Net Assets
For the Years Ended December 31, 2022 and 2021

	2022			2021		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Operating Revenue:						
Program fees	\$ 301,072	\$ 43,773,767	\$ 44,074,839	\$ 182,934	\$ 29,569,500	\$ 29,752,434
Drug, travel and lodging program administrative fees	102,071	4,865,673	4,967,744	44,877	3,288,010	3,332,887
Grants, contributions and bequests	2,683,947	1,177,925	3,861,872	3,363,185	1,132,865	4,496,050
Membership dues	-	2,560,550	2,560,550	-	1,828,085	1,828,085
Special events revenue	2,239,534	15,000	2,254,534	1,888,596	23,500	1,912,096
Registry, web subscriptions and other related fees	781,560	750,300	1,531,860	1,000,570	629,500	1,630,070
Investment return, net	292,249	-	292,249	64,185	-	64,185
Research grants	-	251,881	251,881	-	66,877	66,877
Net assets released from purpose restrictions	34,698,160	(34,698,160)	-	48,069,350	(48,069,350)	-
Net assets released from time restrictions	6,685,723	(6,685,723)	-	5,117,595	(5,117,595)	-
Investment return - endowment, net	(43,287)	-	(43,287)	22,863	-	22,863
Total operating revenue	47,741,029	12,011,213	59,752,242	59,754,155	(16,648,608)	43,105,547
Operating Expenses:						
Patient assistance and reimbursement expense	33,039,892	-	33,039,892	44,198,311	-	44,198,311
Personnel and related	10,723,039	-	10,723,039	10,006,667	-	10,006,667
Conferences, meetings and travel	1,383,887	-	1,383,887	436,255	-	436,255
Professional fees	1,155,992	-	1,155,992	1,180,693	-	1,180,693
Data systems and equipment	514,067	-	514,067	487,430	-	487,430
Occupancy	495,394	-	495,394	497,517	-	497,517
Depreciation	447,010	-	447,010	457,604	-	457,604
Other	431,493	-	431,493	467,025	-	467,025
Research grant expense	198,624	-	198,624	-	-	-
Total operating expenses	48,389,398	-	48,389,398	57,731,502	-	57,731,502
Changes in net assets from operations	(648,369)	12,011,213	11,362,844	2,022,653	(16,648,608)	(14,625,955)
Net Assets:						
Beginning of year	9,168,421	25,773,276	34,941,697	7,145,768	42,421,884	49,567,652
End of year	\$ 8,520,052	\$ 37,784,489	\$ 46,304,541	\$ 9,168,421	\$ 25,773,276	\$ 34,941,697

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, 2022 and 2021

	<u>2022</u>	<u>2021</u>
Cash Flows from Operating Activities:		
Changes in net assets from operations	\$ 11,362,844	\$ (14,625,955)
Adjustments to reconcile changes in net assets to net cash provided by (used in) operating activities:		
Depreciation	447,010	457,604
Bad debt (recovery)	-	(175,000)
Amortization of hosting arrangement costs	117,491	35,772
Changes in operating lease asset	199,613	-
Net gain on investments	(240,420)	(284,135)
Loss on disposal of software under development	8,435	142,169
Changes in operating assets and liabilities:		
Accounts receivable	(9,838,227)	292,543
Prepaid expenses	118,018	17,115
Accounts payable and accrued expenses	(14,344)	185,651
Research grants payable	29,367	(420,935)
Payment of operating lease obligations	(189,215)	-
Deferred revenue	(28,084)	(5,281)
Deferred compensation	(39,914)	38,905
Net cash provided by (used in) operating activities	<u>1,932,574</u>	<u>(14,341,547)</u>
Cash Flows from Investing Activities:		
Proceeds from sales of investments	3,071,668	5,068,536
Proceeds from sale (purchase) of investments - deferred compensation	40,697	(38,905)
Deferred hosting arrangement costs	(149,484)	-
Purchase of investments	(10,025,622)	(224,021)
Investment in software under development	(1,094,757)	(615,837)
Net cash provided by (used in) investing activities	<u>(8,157,498)</u>	<u>4,189,773</u>
Cash Flows from Financing Activities:		
Principal payments on long-term debt	(74,640)	(71,679)
Net Change in Cash and Cash Equivalents	(6,299,564)	(10,223,453)
Cash and Cash Equivalents:		
Beginning of year	<u>13,488,659</u>	<u>23,712,112</u>
End of year	<u>\$ 7,189,095</u>	<u>\$ 13,488,659</u>
Supplemental Disclosure of Cash Flow Information:		
Cash paid for interest	<u>\$ 4,588</u>	<u>\$ 7,958</u>
Supplemental Disclosure of Non-cash Information:		
Non-cash operating lease assets and liabilities obtained in exchange for new or modified leases	<u>\$ 569,633</u>	<u>\$ -</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

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 Financial Accounting Standards Board (FASB) Accounting Standards Codification (ASC).

Recently Adopted Accounting Pronouncement

In February 2016, the FASB issued Accounting Standards Update (ASU) 2016-02, *Leases (Topic 842)*. The most significant change in the new leasing guidance is the requirement to recognize right-of-use (ROU) assets and lease liabilities for operating lease on the statement of financial position. NORD elected to adopt *Topic 842* on January 1, 2022, NORD adopted the new standard and elected the optional transition method, as allowed by ASU 2018-11, *Lease (Topic 842): Targeted Improvements*, to apply the new standard as of the effective date. Therefore, NORD has not applied the new standard to the fiscal year 2021 financial statements.

NORD elected the package of practical expedients permitted under the transition guidance within the new standard, which among other things, allowed NORD to carry forward the historical lease classification as operating or capital leases. NORD did not elect the hindsight practical expedient in determining the lease term for existing leases as of January 1, 2022.

The most significant impact of adoption was the recognition of ROU assets and lease liabilities of \$270,901 and \$278,323, respectively, with differences in amounts being primarily comprised of deferred rent, as of January 1, 2022. NORD expects the impact of adoption to be immaterial to the accompanying statements of activities and changes in net assets and cash flows on an ongoing basis.

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 securities.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Accounts, Grants and Contributions Receivable and Allowance for Doubtful Accounts

Accounts, grants and contributions receivable at December 31, 2022 and 2021, include approximately \$10,883,944 and \$1,036,000, respectively, 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, 2022 and 2021 was \$25,000. As of December 31, 2022 and 2021, accounts, grants and contributions receivable also include contract service receivables of approximately \$195,000 and \$205,000, respectively, representing unconditional rights to consideration 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, grants and contributions 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.

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 assets are valued using Level 1 inputs except as noted in Note 5.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Deferred Hosting Arrangement Costs and Amortization

Implementation costs, including set-up and other upfront fees, which 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, 2022, include unamortized implementation costs related to NORD's budgeting and reporting software, advocacy software, marketing system, website platform, and development software. Deferred hosting arrangement costs as of December 31, 2021, include unamortized implementation costs related to NORD's budgeting and reporting software and development software. The deferred hosting arrangement costs are being amortized through July 2024. Amortization expense was \$117,491 and \$35,772 for the years ended December 31, 2022 and 2021, respectively, and is included in data systems and equipment in the accompanying statements of activities and changes in net assets.

Marketing and Advertising Costs

NORD expenses marketing and advertising costs as they are incurred. At December 31, 2022 and 2021, marketing and advertising costs of \$147,743 and \$240,655, respectively, are included in professional fees in the accompanying statements of activities and changes in net assets.

Research Grants Payable

Research grants are recorded when awarded by NORD. Payments are made when the researchers meet certain milestones. The final payment is made when the research is considered complete. 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 2023 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:

	Estimated Useful Lives
Building and improvements	5 - 20 years
Computer software	2 - 5 years
Furniture and fixtures	5 - 10 years

Land is not depreciated.

Property, equipment and software includes software under development for 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, 2022 and 2021, was \$1,019,516 and \$272,087, respectively, and is included in property, equipment and software, net in the accompanying statements of financial position. When the software update or advance is implemented, it is placed in service and depreciated.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Property, Equipment and Software and Depreciation (Continued)

NORD accounts for the carrying value of its property and equipment in accordance with the requirements of *Impairment and Disposal of Long-Lived Assets*. As of December 31, 2022 and 2021, NORD has not recognized any reduction in the carrying value of its property and equipment in consideration of the requirement.

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 and Board designated endowment - Represents resources available to carry on the operations of NORD and the cumulative earnings on the endowment available for Board approval of spending in line with the investment policy (see Note 4).

Property, equipment and software - Represents the activities relating to NORD's property, equipment and software and ROU assets, net of related debt and lease liabilities, if any.

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).

Net assets with donor restrictions also include endowment funds which are perpetual in nature (see Note 4). Earnings from this fund may be used for operations unless otherwise stipulated by the donor. In accordance with New York law, all earnings, including interest and dividends, and appreciation of a donor-restricted endowment are restricted until appropriated by the Board of Directors, and are released to net assets without donor restrictions based on NORD's spending policy.

As of December 31, 2022 and 2021, net assets with donor restrictions are restricted for the following:

	<u>2022</u>	<u>2021</u>
Purpose restricted	\$ 36,020,489	\$ 24,769,776
Time restricted	1,542,500	782,000
Perpetual in nature	<u>221,500</u>	<u>221,500</u>
Total	<u>\$ 37,784,489</u>	<u>\$ 25,773,276</u>

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Revenue Recognition

In accordance with ASU No. 2018-08, *Not-for-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made*, NORD 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 performance-related barrier or another 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 NORD 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.

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 and changes in net assets 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 fees are recorded as net assets with donor restrictions. When expense criteria is met, patient service program fees revenue is recorded as net assets released from purpose restrictions in the statements of activities and changes in net assets.

Patient service administration fees are recorded as net assets with donor restrictions. When the contract is executed, patient service administration fee revenue is recorded as net assets released from time restrictions in the statements of activities and changes in net assets.

Research grants are received and held as donor restricted contributions until a research grant award is given and are reclassified as net assets released from purpose restrictions in the statements of activities and changes in net assets. Research grants administration fee revenue is withheld from the grant award and released from time restriction upon award date. The research grants administration fee revenue is considered peripheral to the research grant award transaction and is not considered an exchange transaction as no direct benefit is received by the research grant funder.

Sponsorships, included in grants, contributions, and bequests in the statements of activities and changes in net assets, are recorded upon receipt and are recorded as net assets with donor restrictions. When expense criteria is met, revenue is recorded as net assets released from purpose restrictions in the statements of activities and changes in net assets.

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 over time, as time restrictions lapse, and are reported in the statements of activities and changes in net assets as net assets released from time restrictions - membership dues.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

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. Bequests are recorded at a point in time when received. NORD received restricted bequests of \$81,458 and \$494,615 for the years ended December 31, 2022 and 2021, respectively.

NORD evaluates its revenue contracts with customers based on the five-step model under the FASB's ASU No. 2014-09, *Revenue from Contracts with Customers (Topic 606)*: (1) Identify the contract with the customer; (2) Identify the performance obligations in the contract; (3) Determine the transaction price; (4) Allocate the transaction price to separate performance obligations; and (5) Recognize revenue when (or as) each performance obligation is satisfied.

Drug, travel and lodging program administrative fees and registry, web subscriptions and other related fees represent service revenue earned under contractual agreements with customers and is recorded over time 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.

NORD records special events revenue equal to the fair value of direct benefits to donors and contribution income for the excess received when the event takes place. At December 31, 2022 and 2021, there were \$471,133 and \$181,596, respectively, of direct benefits to donors included in special events revenue in the accompanying statements of activities and changes in net assets.

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, 2022 and 2021. 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.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Expense Allocation (Continued)

The financial statements contain certain categories of expenses that are attributable to program and supporting functions and are allocated 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 May 2, 2023, which is the date the financial statements were available to be issued. Other than disclosed in Note 14, there were no events that met the criteria for recognition or disclosure in the financial statements.

Leases

NORD determines if an arrangement is a lease or contains a lease at inception of a contract. A contract is determined to be or contain a lease if the contract conveys the right to control the use of identified property, equipment, or software (an identified asset) in exchange for consideration. NORD determines these assets are leased because NORD has the right to obtain substantially all of the economic benefit from and the right to direct the use of the identified asset. Management only reassesses its determination if the terms and conditions of the contract are changed.

Leases result in the recognition of ROU assets and lease liabilities on the statement of financial position. ROU assets represent the right to use an underlying asset for the lease term, and lease liabilities represent the obligation to make lease payments arising from the lease, measured on a discounted basis. NORD determines lease classification as operating or finance at the later of January 1, 2022, or the lease commencement date.

At lease inception, the lease liability is measured at the present value of the lease payments over the lease term. The ROU asset equals the lease liability adjusted for any initial direct costs, prepaid or deferred rent, and lease incentives. NORD uses the implicit rate when readily determinable. As most of the leases do not provide an implicit rate, NORD uses the risk-free discount rate for the term closest to the full term of the lease, based on the information available at the later of January 1, 2022, or the commencement date to determine the present value of lease payments.

The lease term may include options to extend or to terminate the lease that NORD is reasonably certain to exercise. Lease expense is generally recognized on a straight-line basis over the lease term. NORD recorded rent on a straight-line basis over the terms of the leases in accordance with ASU *Topic 840, Leases*, through fiscal year 2021. Any difference between cash payments in the lease agreements and the related expense for a given year was recorded as deferred rent.

NORD has elected not to record leases with an initial term of twelve months or less on the statements of financial position. Lease expense on such leases is recognized on a straight-line basis over the lease term.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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3. FUNCTIONAL EXPENSES

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

	2022			
	Programs	Supporting Services		Total
		General and Administrative	Development and Communication	
Patient assistance and reimbursement	\$ 33,039,892	\$ -	\$ -	\$ 33,039,892
Personnel and related Conferences, meetings and travel	7,010,894	2,313,466	1,398,679	10,723,039
Professional fees	1,013,954	35,741	334,192	1,383,887
Data systems and equipment	876,197	68,206	211,589	1,155,992
Occupancy	124,885	316,800	72,382	514,067
Depreciation	215,839	225,661	53,894	495,394
Other	415,920	23,013	8,077	447,010
Research grants	250,550	118,452	62,491	431,493
	<u>198,624</u>	<u>-</u>	<u>-</u>	<u>198,624</u>
Total	<u>\$ 43,146,755</u>	<u>\$ 3,101,339</u>	<u>\$ 2,141,304</u>	<u>\$ 48,389,398</u>

	2021			
	Programs	Supporting Services		Total
		General and Administrative	Development and Communication	
Patient assistance and reimbursement	\$ 44,198,311	\$ -	\$ -	\$ 44,198,311
Personnel and related Conferences, meetings and travel	6,544,658	2,122,561	1,339,448	10,006,667
Professional fees	265,052	2,019	169,184	436,255
Data systems and equipment	909,960	230,592	40,141	1,180,693
Occupancy	122,709	322,189	42,532	487,430
Depreciation	216,176	216,777	64,564	497,517
Other	426,512	23,015	8,077	457,604
	<u>214,921</u>	<u>221,153</u>	<u>30,951</u>	<u>467,025</u>
Total	<u>\$ 52,898,299</u>	<u>\$ 3,138,306</u>	<u>\$ 1,694,897</u>	<u>\$ 57,731,502</u>

4. ENDOWMENT

NORD has received \$221,500 of endowments restricted in perpetuity. NORD follows the New York Prudent Management of Institutional Funds Act (NYPMIFA). NORD developed a formal endowment spending policy whereas the corpus shall not be used to pay current expenses, other than investment service fees. The corpus shall be invested, and returns may be used by NORD on an annual basis, starting three years after the funds are invested, with Board approval. The annual spending will be calculated as the greater of zero or half of the average annual return over the prior three years, calculated from the calendar year-end balance.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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4. ENDOWMENT (Continued)

NORD, with Board approval, may decide, at its discretion, to delay or forego the annual withdrawal from the portfolio. NORD will not spend endowed funds from the endowment until after March 2024, three years after the initial investment. There were no amounts appropriated for spending from endowment funds during 2022 and 2021. There were investment service fees paid of \$322 and \$180 as of December 31, 2022 and 2021, respectively. There was a depreciation on endowment funds of \$43,287 as of December 31, 2022. There was appreciation of endowment funds of \$22,863 as of December 31, 2021.

In recognition of the prudence required by fiduciaries, reasonable diversification is sought where possible. Experience has shown financial markets and inflation rates are cyclical, and therefore, control of volatility will be achieved through diversification of asset classes and selection of investment managers of diverse investment styles. Asset allocation parameters have been developed for various funds within the structure, based on investment objectives, liquidity needs, and time horizon for intended use.

Measurement of investment performance against policy objective will be computed on a total return basis. Total return is defined as dividend or interest income plus realized gains and losses and unrealized capital appreciation or depreciation at fair market value.

5. INVESTMENTS

At December 31, 2022 and 2021, investments summarized using the inputs under the ASC Topic, *Fair Value Measurements* standard, consist of the following:

Description	2022			
	Level 1	Level 2	Level 3	Total
Mutual funds	\$ 2,216,630	\$ -	\$ -	\$ 2,216,630
Corporate bonds	-	12,888,305	-	12,888,305
Asset backed securities	-	2,299,244	-	2,299,244
US Treasury bills	-	10,842,925	-	10,842,925
Total investments	\$ 2,216,630	\$ 26,030,474	\$ -	\$ 28,247,104
Investments - Deferred Compensation (see Note 9)				
Mutual Fund	\$ 106,602	\$ -	\$ -	\$ 106,602
Description	2021			
	Level 1	Level 2	Level 3	Total
Mutual funds	\$ 244,654	\$ -	\$ -	\$ 244,654
Corporate bonds	-	14,659,896	-	14,659,896
Asset backed securities	-	5,148,058	-	5,148,058
US Treasury bills	-	1,000,122	-	1,000,122
Total investments	\$ 244,654	\$ 20,808,076	\$ -	\$ 21,052,730
Investments - Deferred Compensation (see Note 9)				
Mutual Fund	\$ 147,299	\$ -	\$ -	\$ 147,299

Investments are not insured and are subject to ongoing market fluctuations.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

6. PROPERTY, EQUIPMENT AND SOFTWARE

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

	<u>2022</u>	<u>2021</u>
Land	\$ 505,203	\$ 505,203
Building and improvements	857,182	857,182
Computer software	3,910,239	3,571,346
Furniture and fixtures	31,731	31,731
Software under development	<u>1,019,516</u>	<u>272,087</u>
	6,323,871	5,237,549
Less - accumulated depreciation	<u>4,163,659</u>	<u>3,716,649</u>
Net property, equipment and software	<u>\$ 2,160,212</u>	<u>\$ 1,520,900</u>

7. 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 3.5% are due in monthly installments of \$6,602 through February 2024, the note's maturity date. Interest paid on the note was \$4,588 and \$7,958 for the years ended December 31, 2022 and 2021, respectively, which is included in other in the accompanying statements of activities and changes in net assets. The balance outstanding on the note was \$90,440 and \$165,080 as of December 31, 2022 and 2021, respectively.

The note agreement contains various covenants with which NORD must comply. At December 31, 2022 and 2021, NORD was in compliance with the covenants.

The future principal payments are as follows:

2023	\$ 77,294
2024	\$ 13,146

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 was extended through December 31, 2023. Borrowings under the agreement are due no later than the expiration date and interest is payable monthly at the London Interbank Offered Rate (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 2022 or 2021.

8. LEASE AGREEMENTS

NORD leases office space under operating leases in Massachusetts and Washington D.C., which expire in July 2025 and April 2024, respectively. The Massachusetts lease was amended and extended in July 2022. Monthly payments under the terms of the agreements were \$16,514 and \$9,026 during 2022 and 2021, respectively. In future years, payments range from \$6,614 to \$10,620. 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.

NORD leases office equipment under various operating leases in Massachusetts, Washington D.C., and Connecticut, which expire between January 2024 and November 2025. Monthly payments under the terms of the agreements were between \$105 to \$1,059 monthly during 2022 and 2021 and are not expected to change in future years.

As of December 31, 2022, there were no material leases that have been executed but not yet commenced.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

8. LEASE AGREEMENTS (Continued)

ASC 840

For the year ended December 31, 2021, NORD recognized rent expense on a straight-line basis over the term of the lease agreements as described in accordance with *Topic 840*. Deferred rent as of the year ended December 31, 2021, was \$7,422, which is included in deferred revenue in the accompanying statements of financial position.

The scheduled minimum lease payments under the lease terms at December 31, 2021:

2022	\$ 199,248
2023	198,168
2024	176,032
2025	<u>127,440</u>
	<u>\$ 700,888</u>

Total occupancy rent expense was \$248,751 for the year ended December 31, 2021, which is included in occupancy in the accompanying 2021 statement of activities and changes in net assets.

ASC 842

As noted on page 6, NORD adopted *Topic 842* on January 1, 2022 by recognizing ROU assets and lease liabilities of \$270,901 and \$278,323, respectively, with differences in amounts being primarily comprised of deferred rent. In July, 2022, as part of the amendment of the Massachusetts lease, NORD recorded an additional asset and liability of \$352,536 recognizing the rights and obligations arising from the new lease arrangement. At December 31, 2022, NORD has recorded ROU assets amounting to \$421,247, and operating lease liability equal to the present value of the future payments of the leases totaling \$431,645 in the accompanying statement of financial position. Cash paid for operating lease obligations totaled \$189,215 at December 31, 2022.

As part of the adoption, NORD considered an asset capitalization threshold of \$12,000 and determined that certain equipment leases were not capitalizable under *Topic 842*. Equipment lease expense of \$5,280 at December 31, 2022 is included in other in the accompanying statements of activities and changes in net assets.

In evaluating its contracts, NORD separately identifies lease and non-lease components, such as common area and other maintenance costs, in calculating the ROU assets and lease liabilities for its office buildings. NORD has elected the practical expedient to not separate lease and non-lease components and classifies the contract as a lease if consideration in the contract allocated to the lease component is greater than the consideration allocated to the non-lease component.

<u>Lease Costs (included in operating expenses):</u>	<u>2022</u>
Operating lease costs	\$ 198,504
Variable lease costs	59,742
Short-term lease costs	<u>5,280</u>
Total lease costs	<u>\$ 263,527</u>

Total occupancy rent expense was \$253,147 for the year ended December 31, 2022, which is included in occupancy in the accompanying 2022 statement of activities and changes in net assets.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2022 and 2021

8. LEASE AGREEMENTS (Continued)

As NORD's current leases do not provide an implicit rate, NORD has elected to use the U.S. Treasury risk-free rate of return based on the information available at the date of adoption or lease commencement date. The weighted average discount rate associated with operating leases for the year ended December 31, 2022, is 1.33%. NORD's weighted average lease term is 1.93 years for the year ended December 31, 2022.

The scheduled minimum lease payments under the lease terms are as follows:

<u>Year Ending December 31</u>	
2023	\$ 215,268
2024	153,635
2025	<u>75,495</u>
Total future undiscounted lease payments	444,398
Less - discount to present value	(12,754)
Less - current portion	<u>(207,322)</u>
Operating Lease liabilities, net of current portion	<u>\$ 224,323</u>

9. EMPLOYMENT BENEFIT PLANS

NORD maintains a tax-deferred pension plan under Section 403(b) of the IRC. Employees may contribute to the plan and NORD contributes into the plan at their discretion.

NORD's contributions for the years ended December 31, 2022 and 2021, totaled \$411,569 and \$360,403, respectively, which are included in personnel and related in the accompanying statements of activities and changes in net assets.

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, 2022 and 2021, are \$106,602 and \$147,299, respectively, which are reflected as 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 statements of financial position date. NORD's contribution expense under the plans was \$19,405 for the year ended December 31, 2021, which is included in personnel and related in the accompanying statements of activities and changes in net assets. There were no contributions to the plan by NORD for the year ended December 31, 2022.

10. 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, 2022 and 2021, 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. Included in cash and cash equivalents is \$767,925 and \$881,916, which are cash accounts held with an investment company which are not insured as of December 31, 2022 and 2021, respectively.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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10. CONCENTRATIONS (Continued)

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

<u>Donor</u>	<u>2022</u>		<u>2021</u>	
	<u>Percentage of Accounts Receivable</u>	<u>Percentage of Total Revenue and Support</u>	<u>Percentage of Accounts Receivable</u>	<u>Percentage of Total Revenue and Support</u>
A	24%	- %	- %	12%
B	63%	28%	- %	20%
C	- %	- %	- %	- %
D	- %	- %	- %	17%
E	- %	- %	- %	11%
F	- %	- %	24%	- %
G	- %	- %	23%	- %
H	- %	- %	10%	- %

11. 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, 2022 and 2021, the balance in the prepaid unemployment insurance account was \$149,677 and \$220,098, 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.

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 7).

For purposes of analyzing resources available to meet general expenditures over a twelve-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 twelve months, NORD anticipates collecting sufficient revenue to cover general expenditures not covered by donor-restricted resources.

As of December 31, 2022 and 2021, the total financial assets held by NORD that could readily be made available within one year of the statements of financial position date to meet general expenditures are as follows:

	<u>2022</u>	<u>2021</u>
Cash and cash equivalents	\$ 7,189,095	\$ 13,488,659
Accounts, grants and contributions receivable, net	11,078,737	1,240,510
Investments	<u>28,046,028</u>	<u>20,808,366</u>
	46,313,860	35,537,535
Less - amounts with donor-imposed restrictions	<u>(36,020,489)</u>	<u>(24,769,776)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 10,293,371</u>	<u>\$ 10,767,759</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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13. CONDITIONAL GRANTS

During 2022, NORD received grants and contributions totaling \$1,424,535, that contained the donor-imposed condition of incurring qualifying expenses, which represent a barrier that must be overcome, as well as a right of return of assets or release from obligations. NORD recognizes these grants and contributions when donor-imposed conditions are substantially met.

14. EMPLOYEE RETENTION TAX CREDIT

The Employee Retention Tax Credit (ERTC) was first established by the Coronavirus Aid, Relief and Economic Security Act (CARES Act) and was extended and expanded by the Consolidated Appropriations Act (CAA) and American Rescue Plan (ARP). ERTC provides a refundable tax credit against certain employment taxes equal to 50% of the first \$10,000 in qualified wages paid to each employee between March 12, 2020 and December 31, 2020 (2020 ERTC), and 70% of the first \$10,000, per quarter, in qualified wages paid to each employee between January 1, 2021 and September 30, 2021 (2021 ERTC). To be eligible, the Organization must meet certain conditions as described in applicable laws and regulations.

Subsequent to year-end, NORD has determined that it qualifies for the 2021 ERTC and will account for the probable refund totaling \$1,874,006 after filing amended 2021 Federal employment tax returns as conditional grants under ASC Subtopic 958-605 in 2023. These grants are conditional upon certain performance requirements and the incurrence of eligible expenses. Eligibility for the credit and the credit calculations are subject to review and approval by the Federal government. As of May 2, 2023, NORD has filed amended 2021 Federal employment tax returns in order to claim the ERTC.