



**FINANCIAL STATEMENTS
DECEMBER 31, 2023 AND 2022**

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Contents
December 31, 2023 and 2022

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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, 2023 and 2022, 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, 2023 and 2022, 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.

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.

Auditor's Responsibilities for the Audit of the Financial Statements (Continued)

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 17, 2024

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Financial Position
December 31, 2023 and 2022

Assets	2023	2022
Current Assets:		
Cash and cash equivalents	\$ 8,100,409	\$ 7,189,095
Accounts, grants and contributions receivable, net	20,885,685	11,078,737
Prepaid expenses	371,112	232,983
Investments	32,890,768	28,046,028
Total current assets	<u>62,247,974</u>	<u>46,546,843</u>
Investments - Deferred Compensation	129,004	106,602
Investments - Endowment	230,004	201,076
Deferred Hosting Arrangement Costs	108,039	106,140
Operating Lease Right-of-Use Asset	529,596	421,247
Property, Equipment and Software, net	<u>1,909,847</u>	<u>2,160,212</u>
Total assets	<u>\$ 65,154,464</u>	<u>\$ 49,542,120</u>
Liabilities and Net Assets		
Current Liabilities:		
Current portion of long-term debt	\$ -	\$ 77,294
Current portion of research grants payable	445,729	752,777
Accounts payable and accrued expenses	2,676,954	1,422,424
Operating lease liability - short-term	226,535	207,322
Deferred revenue	513,639	214,816
Total current liabilities	<u>3,862,857</u>	<u>2,674,633</u>
Research Grants Payable, net of current portion	226,650	218,875
Operating Lease Liability - Long-Term	314,510	224,323
Deferred Compensation	129,004	106,602
Long-Term Debt, net of current portion	<u>-</u>	<u>13,146</u>
Total liabilities	<u>4,533,021</u>	<u>3,237,579</u>
Net Assets:		
Without donor restrictions:		
Operating and board designated endowment	9,296,108	6,460,678
Property, equipment and software	1,898,398	2,059,374
Total without donor restrictions	<u>11,194,506</u>	<u>8,520,052</u>
With donor restrictions	<u>49,426,937</u>	<u>37,784,489</u>
Total net assets	<u>60,621,443</u>	<u>46,304,541</u>
Total liabilities and net assets	<u>\$ 65,154,464</u>	<u>\$ 49,542,120</u>

The accompanying notes are an integral part of these statements.

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NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Activities and Changes in Net Assets
For the Years Ended December 31, 2023 and 2022

	2023			2022		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Operating Revenue:						
Program fees	\$ 439,208	\$ 45,319,169	\$ 45,758,377	\$ 301,072	\$ 43,773,767	\$ 44,074,839
Grants, contributions and bequests	3,767,673	2,200,402	5,968,075	2,683,947	1,928,225	4,612,172
Program administrative fees	132,718	5,036,831	5,169,549	102,071	4,865,673	4,967,744
Investment return, net	2,414,748	-	2,414,748	292,249	-	292,249
Special events revenue	2,379,036	30,000	2,409,036	2,239,534	15,000	2,254,534
Membership dues	-	1,915,500	1,915,500	-	2,560,550	2,560,550
Registry and other fees	752,405	-	752,405	781,560	-	781,560
Research grants	-	78,894	78,894	-	251,881	251,881
Investment return - endowment, net	28,928	-	28,928	(43,287)	-	(43,287)
Net assets released from purpose restrictions	36,814,517	(36,814,517)	-	34,698,160	(34,698,160)	-
Net assets released from time restrictions	6,123,831	(6,123,831)	-	6,685,723	(6,685,723)	-
Total operating revenue	<u>52,853,064</u>	<u>11,642,448</u>	<u>64,495,512</u>	<u>47,741,029</u>	<u>12,011,213</u>	<u>59,752,242</u>
Operating Expenses:						
Patient assistance and reimbursement	35,012,233	-	35,012,233	33,039,892	-	33,039,892
Personnel and related	11,769,993	-	11,769,993	10,723,039	-	10,723,039
Professional fees	2,118,263	-	2,118,263	1,155,992	-	1,155,992
Conferences, meetings and travel	1,575,781	-	1,575,781	1,383,887	-	1,383,887
Depreciation	754,550	-	754,550	447,010	-	447,010
Data systems and equipment	580,005	-	580,005	514,067	-	514,067
Occupancy	534,328	-	534,328	495,394	-	495,394
Other	480,865	-	480,865	431,493	-	431,493
Research grants	29,134	-	29,134	198,624	-	198,624
Total operating expenses	<u>52,855,152</u>	<u>-</u>	<u>52,855,152</u>	<u>48,389,398</u>	<u>-</u>	<u>48,389,398</u>
Changes in net assets from operations before employee retention tax credits and gain on sale of property	(2,088)	11,642,448	11,640,360	(648,369)	12,011,213	11,362,844
Employee Retention Tax Credit	1,927,961	-	1,927,961	-	-	-
Gain on Sale of Property	748,581	-	748,581	-	-	-
Changes in net assets from operations	2,674,454	11,642,448	14,316,902	(648,369)	12,011,213	11,362,844
Net Assets:						
Beginning of year	8,520,052	37,784,489	46,304,541	9,168,421	25,773,276	34,941,697
End of year	<u>\$ 11,194,506</u>	<u>\$ 49,426,937</u>	<u>\$ 60,621,443</u>	<u>\$ 8,520,052</u>	<u>\$ 37,784,489</u>	<u>\$ 46,304,541</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, 2023 and 2022

	<u>2023</u>	<u>2022</u>
Cash Flows from Operating Activities:		
Changes in net assets from operations	\$ 14,316,902	\$ 11,362,844
Adjustments to reconcile changes in net assets to net cash provided by operating activities:		
Depreciation	754,550	447,010
Amortization of hosting arrangement costs	123,690	117,491
Change in allowance for uncollectible accounts	(1,996)	-
Changes in operating lease right-of-use asset	227,586	199,613
Net gain on investments	(2,443,676)	(240,420)
Gain on sale of property	(748,581)	-
Loss on disposal of software under development	-	8,435
Changes in operating assets and liabilities:		
Accounts, grants and contributions receivable	(9,804,952)	(9,838,227)
Prepaid expenses	(138,129)	118,018
Research grants payable	(299,273)	29,367
Accounts payable and accrued expenses	1,254,530	(14,344)
Payment of operating lease liability	(226,535)	(189,215)
Deferred revenue	298,823	(28,084)
Deferred compensation	22,402	(39,914)
Net cash provided by operating activities	<u>3,335,341</u>	<u>1,932,574</u>
Cash Flows from Investing Activities:		
Proceeds from sales of investments	11,289,194	3,071,668
Proceeds from sale (purchase) of investments - deferred compensation	(22,402)	40,697
Deferred hosting arrangement costs	(125,589)	(149,484)
Purchase of investments	(13,719,186)	(10,025,622)
Investment in software under development	(1,055,604)	(1,094,757)
Proceeds from sale of property	1,300,000	-
Net cash used in investing activities	<u>(2,333,587)</u>	<u>(8,157,498)</u>
Cash Flows from Financing Activities:		
Principal payments on long-term debt	(90,440)	(74,640)
Net Change in Cash and Cash Equivalents	911,314	(6,299,564)
Cash and Cash Equivalents:		
Beginning of year	<u>7,189,095</u>	<u>13,488,659</u>
End of year	<u>\$ 8,100,409</u>	<u>\$ 7,189,095</u>
Supplemental Disclosure of Cash Flow Information:		
Cash paid for interest	<u>\$ 1,482</u>	<u>\$ 4,588</u>
Supplemental Disclosure of Non-cash Information:		
Non-cash operating lease assets and liabilities obtained in exchange for new or modified leases	<u>\$ 338,264</u>	<u>\$ 569,633</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2023 and 2022

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).

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 money market accounts, overnight bank deposits, and other short-term highly liquid securities.

Accounts, Grants and Contributions Receivable and Allowance for Doubtful Accounts

Accounts, grants and contributions receivable at December 31, 2023 and 2022, include approximately \$20,631,000 and \$10,883,944, 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, 2023 and 2022, was \$23,004 and \$25,000, respectively. As of December 31, 2023 and 2022, accounts, grants and contributions receivable also include contract service receivables of approximately \$232,000 and \$195,000, respectively, representing unconditional rights to consideration and only the passage of time is required before the payment of that consideration is due. At January 1, 2022, there was contract service receivables of approximately \$205,000 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.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2023 and 2022

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

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, 2023 and 2022, include unamortized implementation costs related to NORD's budgeting and reporting software, advocacy software, marketing system, website platform, and development software. The deferred hosting arrangement costs are being amortized through July 2024. Amortization expense was \$123,690 and \$117,491 for the years ended December 31, 2023 and 2022, 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, 2023 and 2022, marketing and advertising costs of \$215,108 and \$147,743, respectively, are included in professional fees in the accompanying statements of activities and changes in net assets.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2023 and 2022

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

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 2025 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:

	<u>Estimated Useful Lives</u>
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, 2023 and 2022, was \$49,229 and \$1,019,516, 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.

NORD accounts for the carrying value of its property and equipment in accordance with the requirements of *Property, Plant and Equipment*. As of December 31, 2022, NORD had not recognized any reduction in the carrying value of its property and equipment in consideration of the requirement. At December 31, 2023, there were no long-lived assets.

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 right-of-use (ROU) assets, net of related debt and lease liabilities, if any.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2023 and 2022

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Net Assets (Continued)

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, 2023 and 2022, net assets with donor restrictions are restricted for the following:

	<u>2023</u>	<u>2022</u>
Purpose restricted	\$ 46,829,437	\$ 36,020,489
Time restricted	2,376,000	1,542,500
Perpetual in nature	<u>221,500</u>	<u>221,500</u>
Total	<u>\$ 49,426,937</u>	<u>\$ 37,784,489</u>

Revenue Recognition

In accordance with Accounting Standards Update (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.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2023 and 2022

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Revenue Recognition (Continued)

Patient service program 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 and included in program administrative fees with donor restrictions in the accompanying 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.

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 \$563,394 and \$81,458 for the years ended December 31, 2023 and 2022, 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 and other 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. At January 1, 2022, there was deferred revenue of \$242,900. Drug, travel and lodging program administrative fees are included in program administrative fees without donor restrictions in the accompanying statements of activities and changes in net assets.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2023 and 2022

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Revenue Recognition (Continued)

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, 2023 and 2022, there were \$506,867 and \$471,133, 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, 2023 and 2022. 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 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 17, 2024, which is the date the financial statements were available to be issued. There were no events that met the criteria for recognition or disclosure in the financial statements.

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.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2023 and 2022

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Leases (Continued)

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. NORO determines lease classification as operating or finance at 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. NORO uses the implicit rate when readily determinable. As most of the leases do not provide an implicit rate, NORO uses the risk-free discount rate for the term closest to the full term of the lease, based on the information available at 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 NORO is reasonably certain to exercise. Lease expense is generally recognized on a straight-line basis over the lease term. NORO 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.

3. FUNCTIONAL EXPENSES

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

	2023			Total
	Programs	Supporting Services		
		General and Administrative	Development and Communication	
Patient assistance and reimbursement	\$ 35,012,233	\$ -	\$ -	\$ 35,012,233
Personnel and related	7,799,184	2,323,826	1,646,983	11,769,993
Professional fees	1,431,535	353,217	333,511	2,118,263
Conferences, meetings and travel	1,095,272	59,013	421,496	1,575,781
Depreciation	627,298	19,505	107,747	754,550
Data systems and equipment	125,102	365,139	89,764	580,005
Occupancy	223,706	270,494	40,128	534,328
Other	294,028	121,606	65,231	480,865
Research grants	29,134	-	-	29,134
Total	<u>\$ 46,637,492</u>	<u>\$ 3,512,800</u>	<u>\$ 2,704,860</u>	<u>\$ 52,855,152</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2023 and 2022

3. FUNCTIONAL EXPENSES (Continued)

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

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.

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 2023 and 2022. There were investment service fees paid of \$377 and \$322 as of December 31, 2023 and 2022, respectively. There was an appreciation on endowment funds of \$28,928 as of December 31, 2023. There was a depreciation of endowment funds of \$43,287 as of December 31, 2022.

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.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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5. INVESTMENTS

At December 31, 2023 and 2022, investments, including endowment investments, summarized using the inputs under the ASC Topic, *Fair Value Measurements* standard, consist of the following:

<u>Description</u>	2023			Total
	Level 1	Level 2	Level 3	
Mutual funds	\$ 17,014,461	\$ -	\$ -	\$ 17,014,461
Corporate bonds	-	11,200,021	-	11,200,021
Asset backed securities	-	3,814,361	-	3,814,361
U.S. Treasury bills	-	1,091,929	-	1,091,929
Total investments	<u>\$ 17,014,461</u>	<u>\$ 16,106,311</u>	<u>\$ -</u>	<u>\$ 33,120,772</u>
Investments - Deferred Compensation (see Note 9):				
Mutual Fund	<u>\$ 129,004</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 129,004</u>
<u>Description</u>	2022			Total
	Level 1	Level 2	Level 3	
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
U.S. Treasury bills	-	10,842,925	-	10,842,925
Total investments	<u>\$ 2,216,630</u>	<u>\$ 26,030,474</u>	<u>\$ -</u>	<u>\$ 28,247,104</u>
Investments - Deferred Compensation (see Note 9):				
Mutual Fund	<u>\$ 106,602</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 106,602</u>

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

6. PROPERTY, EQUIPMENT AND SOFTWARE

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

	2023	2022
Land	\$ -	\$ 505,203
Building and improvements	-	857,182
Computer software	5,936,127	3,910,239
Furniture and fixtures	31,731	31,731
Software under development	49,229	1,019,516
	<u>6,017,087</u>	<u>6,323,871</u>
Less - accumulated depreciation	<u>4,107,240</u>	<u>4,163,659</u>
Net property, equipment and software	<u>\$ 1,909,847</u>	<u>\$ 2,160,212</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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7. LONG-TERM DEBT AND LINE OF CREDIT

NORD had a mortgage note payable to a bank that was secured by certain property. Payments of principal and interest at 3.5% were due in monthly installments of \$6,602 through February 2024, the note's maturity date. NORD paid off the note payable in full on July 1, 2023. Interest paid on the note was \$1,482 and \$4,588 for the years ended December 31, 2023 and 2022, 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 as of December 31, 2022.

The mortgage note payable contained various covenants with which NORD had to comply. At December 31, 2022, NORD was in compliance with the covenants.

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, 2024. 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 2023 or 2022.

8. LEASE AGREEMENTS

NORD leases office space under operating leases in Massachusetts, Washington D.C. and Connecticut, which expire in July 2025, April 2024 and July 2028, respectively. Total monthly payments under the terms of the agreements were \$23,234 and \$16,514 during 2023 and 2022, respectively. In future years, payments range from \$6,000 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 2023 and 2022 and are not expected to change in future years.

As of December 31, 2023 and 2022, there were no material leases that have been executed but not yet commenced.

At December 31, 2023 and 2022, NORD has recorded ROU assets amounting to \$529,596 and \$421,247, respectively, and operating lease liability equal to the present value of the future payments of the leases totaling \$541,045 and \$431,645, respectively, in the accompanying statements of financial position. Cash paid for operating lease obligations totaled \$226,535 and \$189,215 at December 31, 2023 and 2022, respectively. In August 2023, upon entering into the Connecticut lease, NORD recorded an additional asset and liability of \$343,052 recognizing the rights and obligations arising from the new lease arrangement.

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 \$3,338 and \$5,280 at December 31, 2023 and 2022, respectively, 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.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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8. LEASE AGREEMENTS (Continued)

	<u>2023</u>	<u>2022</u>
Lease Costs (included in operating expenses):		
Operating lease costs	\$ 231,019	\$ 198,504
Variable lease costs	67,706	59,742
Short-term lease costs	<u>3,338</u>	<u>5,280</u>
Total lease costs	<u>\$ 302,063</u>	<u>\$ 263,526</u>

Total occupancy rent expense was \$298,725 and \$258,246 for the years ended December 31, 2023 and 2022, respectively, which is included in occupancy in the accompanying statements of activities and changes in net assets.

The weighted average discount rate associated with operating leases for the years ended December 31, 2023 and 2022, is 1.82% and 1.33%, respectively. NORD's weighted average lease term is 3.17 and 1.93 years for the years ended December 31, 2023 and 2022, respectively.

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

Year Ending December 31:

2024	\$ 226,535
2025	150,582
2026	77,340
2027	79,660
2028	<u>47,271</u>
Total future undiscounted lease payments	581,388
Less - discount to present value	(40,343)
Less - current portion	<u>(226,535)</u>
Operating Lease liabilities, net of current portion	<u>\$ 314,510</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, 2023 and 2022, totaled \$453,742 and \$411,569, 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, 2023 and 2022, are \$129,004 and \$106,602, 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. There were no contributions to the plan by NORD for the year ended December 31, 2023 and 2022.

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Notes to Financial Statements
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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, 2023 and 2022, 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 \$1,027,859 and \$767,925, which are money market accounts held with an investment company which are not insured as of December 31, 2023 and 2022, respectively.

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

Donor	2023		2022	
	Percentage of Accounts Receivable	Percentage of Total Revenue and Support	Percentage of Accounts Receivable	Percentage of Total Revenue and Support
A	18%	- %	13%	- %
B	27%	- %	34%	26%
C	22%	13 %	- %	- %
D	26%	26 %	- %	- %

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, 2023 and 2022, the balance in the prepaid unemployment insurance account was \$170,482 and \$149,677, 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.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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12. LIQUIDITY AND AVAILABILITY OF FINANCIAL ASSETS (Continued)

As of December 31, 2023 and 2022, 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>2023</u>	<u>2022</u>
Cash and cash equivalents	\$ 8,100,409	\$ 7,189,095
Accounts, grants and contributions receivable, net	20,885,685	11,078,737
Investments	<u>32,890,768</u>	<u>28,046,028</u>
	61,876,862	46,313,860
Less - amounts with donor-imposed restrictions	<u>(46,829,437)</u>	<u>(36,020,489)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 15,047,425</u>	<u>\$ 10,293,371</u>

13. CONDITIONAL GRANTS

During fiscal years 2023 and 2022, NORD received grants and contributions totaling \$776,953 and \$1,424,535, respectively, 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, NORD must meet certain conditions as described in applicable laws and regulations.

NORD has determined that it qualifies for the 2021 ERTC and accounted for the refund totaling \$1,927,961 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. In May 2023, NORD filed amended 2021 Federal employment tax returns in order to claim the ERTC. NORD received the ERTC funding during 2023 and those amounts are shown as employee retention tax credit in the accompanying 2023 statement of activities and changes in net assets.