

**NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS**

FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2024 AND 2023



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NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
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INDEPENDENT AUDITORS' REPORT

Board of Directors
National Foundation for Ectodermal Dysplasias
Fairview Heights, Illinois

Report on the Audit of the Financial Statements

Opinion

We have audited the accompanying financial statements of National Foundation for Ectodermal Dysplasias (a nonprofit organization), which comprise the statements of financial position as of December 31, 2024 and 2023, and the related statements of activities, functional expenses, and cash flows for the years then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of National Foundation for Ectodermal Dysplasias as of December 31, 2024 and 2023, 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. Our responsibilities under those standards are further described in the Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of the National Foundation for Ectodermal Dysplasias 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 these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditors' Responsibility 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 auditors' 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 generally accepted auditing standards 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 generally accepted auditing standards, 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 National Foundation for Ectodermal Dysplasias' 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, that raise substantial doubt about National Foundation for Ectodermal Dysplasias' 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.

CliftonLarsonAllen LLP

CliftonLarsonAllen LLP

St. Louis, Missouri
March 24, 2025

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENTS OF FINANCIAL POSITION
DECEMBER 31, 2024 AND 2023

	<u>2024</u>	<u>2023</u>
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	\$ 484,038	\$ 1,068,694
Investments	4,248,503	3,336,835
Pledges Receivable	-	4,389
Prepaid Expenses and Other Assets	19,447	9,919
Total Current Assets	<u>4,751,988</u>	<u>4,419,837</u>
UNCONDITIONAL PLEDGES RECEIVABLE, Net of Current Portion	-	12,798
OPERATING RIGHT OF USE ASSET	<u>39,011</u>	<u>96,688</u>
Total Assets	<u><u>\$ 4,790,999</u></u>	<u><u>\$ 4,529,323</u></u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable	\$ 8,686	\$ 12,995
Treatment Commitments	22,129	13,000
Accrued Expenses	28,496	33,726
Current Lease Liability - Operating	15,805	29,178
Total Current Liabilities	<u>75,116</u>	<u>88,899</u>
Long-Term Lease Liability - Operating, Less Current Maturities	<u>23,206</u>	<u>67,510</u>
Total Liabilities	98,322	156,409
NET ASSETS		
Without Donor Restriction	4,674,445	4,317,747
With Donor Restriction	18,232	55,167
Total Net Assets	<u>4,692,677</u>	<u>4,372,914</u>
Total Liabilities and Net Assets	<u><u>\$ 4,790,999</u></u>	<u><u>\$ 4,529,323</u></u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENT OF ACTIVITIES
YEAR ENDED DECEMBER 31, 2024

	Without Donor Restriction	With Donor Restriction	Total
PUBLIC SUPPORT AND REVENUE			
Contributions of Cash and Other Financial Assets	\$ 971,012	\$ -	\$ 971,012
Contributions of Nonfinancial Assets	20,507	-	20,507
Fundraising Special Events	26,077	-	26,077
Conference Registration Fees	10,275	-	10,275
Sales of Publications/Promotional Items	147	-	147
Investment Gains	536,772	-	536,772
Miscellaneous Revenue	564	-	564
Net Assets Released from Restrictions	36,935	(36,935)	-
Total Public Support and Revenue	<u>1,602,289</u>	<u>(36,935)</u>	<u>1,565,354</u>
EXPENSES			
Program Services:			
Support	546,100	-	546,100
Treatment	261,131	-	261,131
Research	267,566	-	267,566
Supporting Services:			
Management and General	35,176	-	35,176
Fundraising	135,618	-	135,618
Total Expenses	<u>1,245,591</u>	<u>-</u>	<u>1,245,591</u>
NET CHANGE IN NET ASSETS	356,698	(36,935)	319,763
Net Assets - Beginning of Year	<u>4,317,747</u>	<u>55,167</u>	<u>4,372,914</u>
NET ASSETS - END OF YEAR	<u><u>\$ 4,674,445</u></u>	<u><u>\$ 18,232</u></u>	<u><u>\$ 4,692,677</u></u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENT OF ACTIVITIES
YEAR ENDED DECEMBER 31, 2023

	Without Donor Restriction	With Donor Restriction	Total
PUBLIC SUPPORT AND REVENUE			
Contributions of Cash and Other Financial Assets	\$ 884,423	\$ -	\$ 884,423
Contributions of Nonfinancial Assets	6,778	-	6,778
Fundraising Special Events	38,504	-	38,504
Conference Registration Fees	29,121	-	29,121
Sales of Publications/Promotional Items	2,879	-	2,879
Investment Gains	698,711	-	698,711
Net Assets Released from Restrictions	61,970	(61,970)	-
Total Public Support and Revenue	<u>1,722,386</u>	<u>(61,970)</u>	<u>1,660,416</u>
EXPENSES			
Program Services:			
Support	521,415	-	521,415
Treatment	258,933	-	258,933
Research	191,396	-	191,396
Supporting Services:			
Management and General	15,690	-	15,690
Fundraising	108,699	-	108,699
Total Expenses	<u>1,096,133</u>	<u>-</u>	<u>1,096,133</u>
NET CHANGE IN NET ASSETS	626,253	(61,970)	564,283
Net Assets - Beginning of Year	<u>3,691,494</u>	<u>117,137</u>	<u>3,808,631</u>
NET ASSETS - END OF YEAR	<u><u>\$ 4,317,747</u></u>	<u><u>\$ 55,167</u></u>	<u><u>\$ 4,372,914</u></u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED DECEMBER 31, 2024

	Program Services			Management and		
	Support	Treatment	Research	General	Fundraising	Total
Total Salaries and Related Expenses	\$ 250,824	\$ 178,117	\$ 134,716	\$ 8,723	\$ 56,521	\$ 628,901
Board of Directors Expense	3,499	1,428	928	71	1,214	7,140
Client Assistance	-	16,569	-	-	-	16,569
Development	8,946	8,307	8,308	6,390	31,951	63,902
Family Conferences	161,004	-	-	-	-	161,004
In-Kind - Professional and Other	11,168	4,467	3,350	447	2,904	22,336
Insurance	3,593	1,466	953	73	1,247	7,332
Marketing/ Communications	8,988	3,595	2,695	359	2,337	17,974
Memberships	8,507	3,472	2,257	174	2,951	17,361
Miscellaneous	1,347	388	404	53	350	2,542
Office - General	17,514	8,121	5,852	15,682	5,507	52,676
Professional Fees	54,950	22,428	14,579	1,121	19,065	112,143
Repairs and Maintenance	353	144	94	7	123	721
Research Funding	-	-	81,423	-	-	81,423
Special Events	2,782	2,583	2,584	1,987	9,936	19,872
Advocacy	8,268	8,268	8,267	-	-	24,803
Utilities	4,357	1,778	1,156	89	1,512	8,892
Total Expenses	<u>\$ 546,100</u>	<u>\$ 261,131</u>	<u>\$ 267,566</u>	<u>\$ 35,176</u>	<u>\$ 135,618</u>	<u>\$ 1,245,591</u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED DECEMBER 31, 2023

	Program Services			Management and General	Fundraising	Total
	Support	Treatment	Research			
Total Salaries and Related Expenses	\$ 223,351	\$ 166,601	\$ 115,676	\$ 7,950	\$ 45,487	\$ 559,065
Board of Directors Expense	917	374	243	19	318	1,871
Client Assistance	-	9,391	-	-	-	9,391
Depreciation	-	-	-	-	-	-
Development	5,911	5,489	5,489	4,223	21,111	42,223
Family Conferences	142,552	-	-	-	-	142,552
Family Support Network	258	-	-	-	-	258
In-Kind - Professional and Other	5,583	2,233	1,675	223	1,452	11,166
Insurance	4,514	1,842	1,198	92	1,566	9,212
Marketing/ Communications	21,102	8,441	6,331	844	5,486	42,204
Memberships	6,170	2,434	1,637	126	2,140	12,507
Miscellaneous	2,841	1,212	869	87	837	5,846
Office - General	14,130	5,767	3,749	289	4,902	28,837
Professional Fees	60,497	24,693	16,050	1,235	20,989	123,464
Repairs and Maintenance	462	189	123	9	160	943
Research Funding	-	-	8,796	-	-	8,796
Special Events	725	674	674	518	2,591	5,182
Advocacy	27,617	27,617	27,617	-	-	82,851
Utilities	4,785	1,976	1,269	75	1,660	9,765
Total Expenses	<u>\$ 521,415</u>	<u>\$ 258,933</u>	<u>\$ 191,396</u>	<u>\$ 15,690</u>	<u>\$ 108,699</u>	<u>\$ 1,096,133</u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENTS OF CASH FLOWS
YEARS ENDED DECEMBER 31, 2024 AND 2023

	<u>2024</u>	<u>2023</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
Net Change in Net Assets	\$ 319,763	\$ 564,283
Adjustments to Reconcile Net Change in Net Assets to Cash and Cash Equivalents Used by Operating Activities:		
Donated Investments	(60,513)	(59,225)
Investment Gain	(374,725)	(650,142)
(Increase) Decrease in:		
Pledges Receivable	17,187	4,388
Prepaid Expenses and Other Assets	(9,528)	13,548
Increase (Decrease) in:		
Accounts Payable	(4,309)	7,831
Commitments	9,129	6,900
Accrued Expenses	(5,230)	(24,668)
Net Cash and Cash Equivalents Used by Operating Activities	<u>(108,226)</u>	<u>(137,085)</u>
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Investments	(1,315,454)	(929,338)
Proceeds from Sale of Investments	<u>839,024</u>	<u>1,362,572</u>
Net Cash and Cash Equivalents Provided (Used) by Investing Activities	<u>(476,430)</u>	<u>433,234</u>
NET CHANGE IN CASH AND CASH EQUIVALENTS	(584,656)	296,149
Cash and Cash Equivalents - Beginning of Year	<u>1,068,694</u>	<u>772,545</u>
CASH AND CASH EQUIVALENTS - END OF YEAR	<u><u>\$ 484,038</u></u>	<u><u>\$ 1,068,694</u></u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2024 AND 2023

NOTE 1 ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of Operations

National Foundation for Ectodermal Dysplasias (NFED) is a nonprofit organization whose mission is to empower and connect people touched by Ectodermal Dysplasias through education, support, and research.

Description of Programs and Support Activities

The accompanying financial statements include the following program services and supporting activities:

Support – NFED publishes high quality information to provide families with knowledge that will increase their quality of life. Information is shared through the First Connect Program, a web site, medical/dental guide series, and conferences. The National Family Conference is NFED's hallmark program bringing entire families together to learn, share, and network with one another and with expert care providers. Affected children and their siblings attend Kids Camp at the conferences where they participate in educational and social activities with other children like them to develop self-esteem. NFED provides financial assistance to individuals to attend the Family Conference. NFED's Family-to-Family Network connects families with a caring liaison in their region who can provide moral support, information and practical advice, guidance, and resources.

Treatment – NFED's Patient Care Council, comprised of medical and dental Experts, oversees the NFED's initiatives to improve treatment of ectodermal dysplasias. NFED teaches care providers how to diagnose and treat the rare disorders through professional symposia and Grand Rounds at universities. NFED advocates for improving access to care with sponsoring legislation to cover congenital anomalies, and collaborating with universities, government, patient health organizations. Affected individuals can receive more affordable care from experienced teams of dentists in treatment of ectodermal dysplasias at NFED Dental Treatment Centers in the U.S. NFED also helps families pay for needed care through the Treatment Assistance Program and insurance coaching.

Research – NFED's Scientific Advisory Council oversees the NFED's research initiatives, aimed to improve the health and quality of life of affected individuals by finding management solutions and, eventually, finding cures for ectodermal dysplasias. NFED advances research through advocacy and partnerships with organizations such as the National Institute of Health. NFED provides seeds funds to researchers, provides them with access to affected individuals, and shares information to launch larger projects. NFED is developing a web-based Ectodermal Dysplasias International Registry to serve as a repository of genetic and clinical information and facilitates communication among scientists who strive to advance research on ectodermal dysplasias. NFED also sponsors scientific meetings to increase understanding of the disorders.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2024 AND 2023

NOTE 1 ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES
(CONTINUED)

Description of Programs and Support Activities (Continued)

Management and General – These activities include functions necessary to administer and manage office operations and all programs. It also includes legal, financial, and fiduciary requirements.

Fundraising – These activities include development and fundraising efforts necessary to promote and acquire financial support from individuals, organizations, and corporations in order to meet the mission of NFED.

Basis of Presentation

Net assets, revenues, expenses, gains, and losses are classified based on the existence or absence of donor-imposed restrictions. Accordingly, net assets and the changes therein are classified and reported as follows:

Net Assets Without Donor Restrictions – Net assets available for use in general operations and not subject to donor-imposed stipulations.

Net Assets with Donor Restrictions – Net assets subject to donor-imposed stipulations that may be met by actions of NFED and/or the passage of time. Other net assets require that they be maintained in perpetuity by NFED. Generally, the donors of these assets permit NFED to use all or part of the income earned on related investments for specific purposes. NFED did not have net assets to be maintained in perpetuity at December 31, 2024 and 2023.

Basis of Accounting

The financial statements of NFED have been prepared on the accrual basis of accounting in accordance with accounting principles generally accepted in the United States of America.

Use of Estimates

The preparation of the financial statements in conformity with accounting principles generally accepted in the United States of America 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 support, revenues, and expenses during the reporting period including grant and contract revenues subject to review by applicable funding agencies. Accordingly, actual results could differ from those estimates.

Cash and Cash Equivalents

For purposes of balance sheet presentation and reporting of cash flows, cash and cash equivalents include unrestricted demand deposits and money market funds. Short-term cash equivalents that are managed as part of long-term investment strategies are included with investments.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2024 AND 2023

NOTE 1 ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES
(CONTINUED)

Pledges

NFED receives pledges in the form of grants and contributions. Pledges, including unconditional promises to give cash and other assets to NFED in the future, are recognized as revenue at fair value in the period received. The gifts are reported as with donor restrictions if they are received with donor stipulations that limit the use of the donated assets. 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 as net assets without donor restrictions and reported in the statement of operations as net assets released from restrictions. Donor-imposed contributions whose restrictions are met in the same year as received are reported as unrestricted contributions in the accompanying financial statements. Unconditional promises to give in subsequent years are reflected as pledges receivable and are recorded at the face value of the expected future cash flows. Based on management's assessment of the pledge receivable, they have concluded an allowance for doubtful accounts for pledge receivables would be immaterial.

Investments

Investments are recorded in accordance with *Accounting for Certain Investments Held by Not-for-Profit Organizations*. As such, investments in marketable securities with readily determinable fair values are reported at fair value in the statement of financial position. Unrealized gains and losses are included in the statement of activities.

Property and Equipment

It is NFED's policy to capitalize property and equipment over \$5,000. Lesser amounts are expensed. Purchased property and equipment is capitalized at cost. Donations of property and equipment are recorded as contributions at their estimated fair value. Depreciation is computed using the straight-line method over the estimated useful lives of the assets.

Other Assets

Other assets consist primarily of auction items donated for NFED's various fundraising events. These items are recorded at estimated fair value, as determined by management, at the time of receipt.

Tax Status

NFED is tax-exempt under Section 501(c)(3) of the Internal Revenue Code and, therefore, is exempt from both federal and state income taxes. Accordingly, no provision has been made for income taxes in the accompanying financial statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2024 AND 2023

NOTE 1 ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES
(CONTINUED)

Donated Materials and Services

Donated property and equipment, investments and other noncash donations are recorded as contributions at their fair value at the date of donation. NFED reports the donations as support without donor restrictions, unless explicit donor stipulations specify how the assets must be used. Gifts of long-lived assets with explicit restrictions that specify how the assets must be used, and gifts of cash or other assets that must be used to acquire long-lived assets, are reported as support with donor restrictions. Absent explicit donor stipulations about how those long-lived assets must be maintained, NFED reports expirations of donor restrictions when the assets are placed in service. NFED records donated property, equipment, and services related to fundraising special events as In-Kind Donations to Fundraising Special Events Revenue and In-Kind Special Events Expense.

NFED records the value of donated services when there is an objective basis available to measure the donation's value. In addition, many individuals' volunteer time and skills to perform a variety of tasks that assist NFED, but these services do not meet the criteria for recognition as donated services.

In-kind donations in 2024 balance consisted primarily of special events donations. In 2023, balance consisted primarily of special event donations, board of directors' travel expenses, and office rent donated by NFED's landlord. The in-kind office rent donation, which is a discount of \$2 per square foot of office space, totaled \$65,820, and will be released from restriction over the term of the lease agreement, which began in December 2012 and was extended in 2017 through June 2024.

Functional Expenses

NFED allocates its expenses on a functional basis to its programs and supporting services. Expenses that can be identified with a specific program and supporting service are allocated directly according to their natural expenditure classification. Expenses that are common to several functions are primarily allocated based on management's estimate of job descriptions.

Treatment and Research Commitments

Unconditional grants to third parties are recorded as program expenses in the period in which the grants are authorized. Conditional grants or contributions are recorded as expense in the period in which the conditions have been substantially met by the grantee.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2024 AND 2023

NOTE 1 ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES
(CONTINUED)

Fair Value Measurements

Financial assets have been disclosed at their respective fair values or measured at the price that would be received to sell an asset or paid to transfer a liability in an orderly transaction between market participants at the measurement date on a recurring basis. The financial assets are valued using the following fair value hierarchy in order to disclose the measurement of fair value based on three levels of observable or unobservable inputs:

Level 1 – Quoted prices (unadjusted) in active markets for identical assets that NFED has the ability to access as of the measurement date.

Level 2 – Significant other observable inputs other than Level 1 prices, such as quoted prices for similar assets or liabilities, quoted prices in markets that are not active, and other inputs that are observable or can be corroborated by observable market data.

Level 3 – Significant unobservable inputs that reflect NFED's own assumptions about the assumptions that market participants would use in pricing the asset, based on the best information available in the circumstances.

Following is a description of the valuation methodologies used for assets measured at fair value:

Mutual Funds: Valued at the closing price reported on the active market on which the individual funds are traded.

Equity Securities: Valued at the closing price reported on the active market on which the individual funds are traded.

Exchange Traded Funds: Valued at the closing price reported on the active market on which the individual funds are traded.

Concentration of Credit Risk

NFED maintains a portion of its cash and investments in deposit and fund accounts that at times may exceed federally insured limits. NFED has not experienced any losses in such accounts. NFED believes it is not exposed to any significant credit risk on its cash and investments.

Subsequent Events

In preparing these financial statements, NFED has evaluated events and transactions for potential recognition or disclosure through March 24, 2025, the date the financial statements were available to be issued.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2024 AND 2023

NOTE 1 ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES
(CONTINUED)

Leases

NFED leases office space, a copier, and a postage machine. NFED determines if an arrangement is a lease at inception. Operating leases are included in operating lease right-of-use (ROU) assets and operating lease liabilities on the statements of financial position.

ROU assets represent NFED's right to use an underlying asset for the lease term and lease liabilities represent NFED's obligation to make lease payments arising from the lease. ROU assets and liabilities are recognized at commencement date based on the present value of lease payments over the lease term. As most of leases do not provide an implicit rate, NFED uses the incremental borrowing rate at commencement date in determining the present value of lease payments. The operating lease ROU asset also includes any lease payments made and excludes lease incentives. The lease terms may include options to extend or terminate the lease when it is reasonably certain that NFED will exercise that option. Lease expense for operating lease payments is recognized on a straight-line basis over the lease term. NFED has elected to recognize payments for short-term leases with a lease term of 12 months or less as expense as incurred and these leases are not included as lease liabilities or right of use assets on the balance sheet.

NFED has elected not to separate nonlease components from lease components and instead accounts for each separate lease component and the nonlease component as a single lease component. NFED's lease agreements do not contain any material residual value guarantees or material restrictive covenants.

NOTE 2 PROPERTY AND EQUIPMENT

Property and equipment consists of the following at December 31:

	2024	2023
Furnishings, Fixtures, and Equipment	\$ 41,323	\$ 41,323
Less: Accumulated Depreciation	(41,323)	(41,323)
Total Net of Depreciation	<u>\$ -</u>	<u>\$ -</u>

There was no depreciation expense for the years ended December 31, 2024 and 2023, respectively.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2024 AND 2023

NOTE 3 INVESTMENTS

Investments at fair value consist of the following at December 31:

	2024	2023
Level 1 Assets:		
Stocks	\$ 1,259,795	\$ 1,127,082
Mutual Funds:	1,661,657	1,483,455
Exchange Traded Funds	783,076	704,933
Real Estate Index Funds	35,856	21,365
Total Level 1 Assets	<u>\$ 3,740,384</u>	<u>\$ 3,336,835</u>
Level 2 Assets:		
U.S. Treasury Securities	\$ 153,761	\$ -
Corporate Bonds	169,906	-
Municipal Bonds	4,344	-
Asset-Backed Securities	180,108	-
Total Level 2 Assets	<u>\$ 508,119</u>	<u>\$ -</u>

Investment return for the years ended December 31 is summarized as follows:

	2024	2023
Interest and Dividends	\$ 162,047	\$ 48,569
Realized Investment Gains	79,395	163,091
Unrealized Investment Gains (Losses)	295,330	487,051
Total	<u>\$ 536,772</u>	<u>\$ 698,711</u>

NOTE 4 PLEDGES RECEIVABLE

Pledges receivable are due as follows:

	2024	2023
Due in Less Than One Year	\$ -	\$ 4,389
Due in One to Five Years	-	12,798
Face Value of Pledges Receivable	<u>\$ -</u>	<u>\$ 17,187</u>

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
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NOTE 5 LIQUIDITY AND AVAILABILITY

Financial assets available for grants, treatment, research, support, and other expenses within one year of the statements of financial position date comprise the following at December 31:

	2024	2023
Cash and Equivalents	\$ 484,038	\$ 1,068,694
Investments	4,248,503	3,336,835
Financial Assets Available for Expenses	4,732,541	4,405,529
Purpose Restricted Expenses	(18,232)	(37,983)
Financial Assets Available to Meet Cash Needs for General Expenditures Within One Year	<u>\$ 4,714,309</u>	<u>\$ 4,367,546</u>

NOTE 6 NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions are available for the following purposes or periods at December 31:

	2024	2023
In-Kind Rent	\$ -	\$ 17,184
Research Program	18,232	37,983
Total Net Assets with Donor Restrictions	<u>\$ 18,232</u>	<u>\$ 55,167</u>

Net assets released from donor restrictions for the years ended December 31 are as follows:

	2024	2023
Research Program	\$ 19,751	\$ 57,581
In-Kind Rent	17,184	4,389
Total	<u>\$ 36,935</u>	<u>\$ 61,970</u>

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NOTE 7 TREATMENT AND RESEARCH COMMITMENTS

Commitments payable (at face value) for treatment and research are to be paid as follows:

	2024	
	Treatment	Research
Due in Less Than One Year	\$ 22,129	\$ -
Due in One to Five Years	-	-
Total	<u>\$ 22,129</u>	<u>\$ -</u>

	2023	
	Treatment	Research
Due in Less Than One Year	\$ 13,000	\$ -
Due in One to Five Years	-	-
Total	<u>\$ 13,000</u>	<u>\$ -</u>

Family conference scholarships are generally committed and expensed in the same fiscal year and did not have any outstanding commitments at December 31, 2024 or 2023.

NOTE 8 LEASES

NFED rents office space and certain office equipment under operating lease arrangements that expire at various dates through December 2027. In the normal course of business, it is expected that these leases will be renewed or replaced by similar leases.

The following table provides quantitative information concerning NFED's leases as of and for the years ended December 31:

	2024	2023
Lease Costs:		
Operating Lease Costs	\$ 25,156	\$ 29,178
Total Building and Equipment Lease Costs	<u>\$ 25,156</u>	<u>\$ 29,178</u>
Other Information:		
Cash Paid for Amounts Included in the Measurement of Lease Liabilities:		
Operating Cash Flows from Operating Leases	\$ 23,145	\$ 29,178
Weighted-Average Remaining Lease Term - Operating Leases	2.6 Years	3.6 Years
Weighted-Average Discount Rate - Operating Leases	4.08%	4.14%

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NOTE 8 LEASES (CONTINUED)

NFED classifies the total undiscounted lease payments that are due in the next 12 months as current. A maturity analysis of annual undiscounted cash flows for lease liabilities as of December 31, 2024, is as follows:

<u>Year Ending December 31,</u>	<u>Operating Leases</u>
2025	\$ 17,111
2026	13,877
2027	10,056
Total Lease Payments	41,044
Less: Interest	(2,033)
Total	<u>\$ 39,011</u>

NOTE 9 EMPLOYEE BENEFIT PLAN

NFED provides a SIMPLE individual retirement plan to substantially all employees. At their discretion NFED's board of directors may approve NFED contributions to the Plan. In 2024 and 2023, contribution expenses totaled \$10,528 and \$9,445, respectively.

NOTE 10 NONFINANCIAL CONTRIBUTIONS

Donated goods and services of \$20,507 and \$6,778 have been reflected in the financial statements for the years ended December 31, 2024 and 2023 respectively, including items such as rent, apparel, and various auction items for special events. All donated items are used by NFED, not monetized, and did not have donor-imposed restrictions associated with them. NFED estimates the fair value of donated in-kind goods on the basis of estimates of the current market rates for similar goods and services in the Organization's market. A summary of nonfinancial assets contributed is as follows:

	<u>2024</u>	<u>2023</u>
Board In-Kind	\$ 2,709	\$ 2,470
Special Event In-Kind	17,798	4,308
Total In-Kind	<u>\$ 20,507</u>	<u>\$ 6,778</u>

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NOTE 11 SPECIAL EVENT REVENUE

Special events revenue comprise an exchange element based on the value of the benefits provided and a contribution element for the different between the total support and the exchange element. The exchange element is recognized over time as the event occurs. During the years ended December 31, the contribution and exchange revenue included the following:

	<u>2024</u>	<u>2023</u>
Contribution Revenue (Reported as Contributions)	\$ 170,157	\$ 107,729
Exchange Revenue		
Auction	26,077	16,299
Registration (Reported as Contributions)	21,515	22,205
Total Special Event Revenue	<u>\$ 217,749</u>	<u>\$ 146,233</u>



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