

**NATIONAL FOUNDATION FOR  
ECTODERMAL DYSPLASIAS**

**FINANCIAL STATEMENTS**

**YEARS ENDED DECEMBER 31, 2022 AND 2021**



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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, 2022 and 2021, 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, 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. 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**

St. Louis, Missouri  
March 30, 2023

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**STATEMENTS OF FINANCIAL POSITION**  
**DECEMBER 31, 2022 AND 2021**

	2022	2021
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and Cash Equivalents	\$ 772,545	\$ 734,683
Investments	3,060,702	3,525,150
Pledges Receivable	4,389	4,389
Accounts Receivable	-	45,724
Prepaid Expenses and Other Assets	23,467	8,123
Total Current Assets	3,861,103	4,318,069
<b>UNCONDITIONAL PLEDGES RECEIVABLE</b> , Net of Current Portion	17,186	21,574
<b>OPERATING RIGHT OF USE ASSET</b>	121,290	-
Total Assets	\$ 3,999,579	\$ 4,339,643
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts Payable	\$ 5,164	\$ 2,711
Treatment Commitments	6,100	9,177
Accrued Expenses	58,394	46,878
Current Lease Liability - Operating	29,178	-
Total Current Liabilities	98,836	58,766
Long-Term Lease Liability - Operating (Less Current Maturities)	92,112	-
Total Liabilities	190,948	58,766
<b>NET ASSETS</b>		
Without Donor Restriction	3,691,494	4,158,034
With Donor Restriction	117,137	122,843
Total Net Assets	3,808,631	4,280,877
Total Liabilities and Net Assets	\$ 3,999,579	\$ 4,339,643

See accompanying Notes to Financial Statements.

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**STATEMENT OF ACTIVITIES**  
**YEAR ENDED DECEMBER 31, 2022**

	Without Donor Restriction	With Donor Restriction	Total
<b>PUBLIC SUPPORT AND REVENUE</b>			
Contributions of Cash and Other Financial Assets	\$ 1,151,307	\$ 19,377	\$ 1,170,684
Contributions of Nonfinancial Assets	35,537	-	35,537
Fundraising Special Events	61,437	-	61,437
Conference Registration Fees	24,687	-	24,687
Sales of Publications/Promotional Items	3,786	-	3,786
Investment Losses	(622,808)	-	(622,808)
Net Assets Released from Restrictions	25,083	(25,083)	-
Total Public Support and Revenue	679,029	(5,706)	673,323
<b>EXPENSES</b>			
Program Services:			
Support	485,406	-	485,406
Treatment	262,989	-	262,989
Research	196,939	-	196,939
Supporting Services:			
Management and General	17,148	-	17,148
Fundraising	183,088	-	183,088
Total Expenses	1,145,569	-	1,145,569
<b>NET CHANGE IN NET ASSETS</b>	(466,540)	(5,706)	(472,246)
Net Assets - Beginning of Year	4,158,034	122,843	4,280,877
<b>NET ASSETS - END OF YEAR</b>	\$ 3,691,494	\$ 117,137	\$ 3,808,631

See accompanying Notes to Financial Statements.

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**STATEMENT OF ACTIVITIES**  
**YEAR ENDED DECEMBER 31, 2021**

	Without Donor Restriction	With Donor Restriction	Total
<b>PUBLIC SUPPORT AND REVENUE</b>			
Contributions of Cash and Other Financial Assets	\$ 1,252,152	\$ 65,523	\$ 1,317,675
Contributions of Nonfinancial Assets	12,452	-	12,452
Fundraising Special Events	42,265	-	42,265
Conference Registration Fees	4,580	-	4,580
Sales of Publications/Promotional Items	803	-	803
Investment Income	486,159	-	486,159
Gain on Extinguishment of PPP Loan	94,772	-	94,772
Employee Retention Credits	88,501	-	88,501
Net Assets Released from Restrictions	22,970	(22,970)	-
Total Public Support and Revenue	2,004,654	42,553	2,047,207
<b>EXPENSES</b>			
Program Services:			
Support	308,948	-	308,948
Treatment	198,376	-	198,376
Research	216,433	-	216,433
Supporting Services:			
Management and General	13,068	-	13,068
Fundraising	158,059	-	158,059
Total Expenses	894,884	-	894,884
<b>NET CHANGE IN NET ASSETS</b>	1,109,770	42,553	1,152,323
Net Assets - Beginning of Year	3,048,264	80,290	3,128,554
<b>NET ASSETS - END OF YEAR</b>	\$ 4,158,034	\$ 122,843	\$ 4,280,877

See accompanying Notes to Financial Statements.

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**STATEMENT OF FUNCTIONAL EXPENSES**  
**YEAR ENDED DECEMBER 31, 2022**

	Program Services			Management and	Fundraising	Total
	Support	Treatment	Research	General		
Total Salaries and Related Expenses	\$ 224,287	\$ 169,041	\$ 125,460	\$ 7,483	\$ 114,745	\$ 641,016
Board of Directors Expense	362.60	148.00	103.60	7.40	118.40	740.00
Client Assistance	-	16,281	-	-	-	16,281
Depreciation	7,336	5,206	4,733	1,657	4,733	23,665
Development	3,264	3,030	3,030	2,331	11,652	23,307
Family Conferences	103,582	-	-	-	-	103,582
Family Support Network	350	-	-	-	-	350
In-Kind - Professional and Other	19,962	7,985	5,989	798	5,190	39,924
Insurance	2,991	1,221	794	61	1,037	6,104
Marketing/Communications	23,930	9,572	7,179	957	6,223	47,861
Memberships	20,112	8,209	5,336	410	6,979	41,046
Miscellaneous	4,140	1,690	1,098	84	1,436	8,448
Office - General	5,911	2,413	1,568	121	2,050	12,063
Professional Fees	45,924	18,744	12,184	937	15,933	93,722
Repairs and Maintenance	681	278	181	14	237	1,391
Research Funding	-	-	10,884	-	-	10,884
Special Events	3,049	2,831	2,831	2,177	10,887	21,773
Advocacy	14,142	14,143	14,140	-	-	42,425
Utilities	5,383	2,197	1,428	110	1,867	10,985
<b>Total Expenses</b>	<b>\$ 485,406</b>	<b>\$ 262,989</b>	<b>\$ 196,939</b>	<b>\$ 17,148</b>	<b>\$ 183,088</b>	<b>\$ 1,145,569</b>

See accompanying Notes to Financial Statements.



**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**STATEMENT OF FUNCTIONAL EXPENSES**  
**YEAR ENDED DECEMBER 31, 2021**

	Program Services			Management and	Fundraising	Total
	Support	Treatment	Research	General		
Total Salaries and Related Expenses	\$ 185,113	\$ 135,831	\$ 100,460	\$ 6,447	\$ 104,739	\$ 532,590
Board of Directors Expense	2,101	858	600	43	686	4,288
Client Assistance	-	9,500	-	-	-	9,500
Development	4,374	4,063	4,063	3,125	15,627	31,248
Family Conferences	9,391	-	-	-	-	9,391
Family Support Network	630	-	-	-	-	630
In-Kind - Professional and Other	6,319	2,510	1,926	294	1,503	12,552
Insurance	3,912	1,597	1,038	80	1,357	7,984
Marketing/ Communications	15,611	6,244	4,683	624	4,059	31,221
Memberships	6,238	2,546	1,655	127	2,164	12,729
Miscellaneous	1,627	663	432	33	566	3,325
Office - General	10,521	4,294	2,791	215	3,650	21,471
Professional Fees	38,146	15,552	10,120	778	13,234	77,830
Rent - Building	11,826	4,827	3,379	241	3,861	24,134
Repairs and Maintenance	465	190	123	9	161	949
Research Funding	-	-	76,156	-	-	76,156
Special Events	1,334	1,239	1,239	953	4,765	9,530
Advocacy	6,477	6,477	6,478	-	-	19,432
Utilities	4,863	1,985	1,290	99	1,687	9,924
<b>Total Expenses</b>	<b>\$ 308,948</b>	<b>\$ 198,376</b>	<b>\$ 216,433</b>	<b>\$ 13,068</b>	<b>\$ 158,059</b>	<b>\$ 894,884</b>

See accompanying Notes to Financial Statements.

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**STATEMENTS OF CASH FLOWS**  
**YEARS ENDED DECEMBER 31, 2022 AND 2021**

	2022	2021
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Net Change in Net Assets	\$ (472,246)	\$ 1,152,323
Adjustments to Reconcile Net Change in Net Assets to Cash and Cash Equivalents Provided by Operating Activities:		
Donated Investments	(114,300)	(449,149)
Proceeds from Sale of Donated Investments	-	333,020
Investment (Gain) Loss	658,875	(460,378)
(Increase) Decrease in:		
Pledges Receivable	4,388	4,388
Accounts Receivable	45,724	(45,724)
Prepaid Expenses and Other Assets	(15,344)	2,863
Increase (Decrease) in:		
Accounts Payable	2,453	1,917
Commitments	(3,077)	(5,023)
Accrued Expenses	11,516	15,784
Net Cash and Cash Equivalents Provided by Operating Activities	117,989	550,021
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Purchases of Investments	(3,450,349)	(1,578,116)
Proceeds from Sale of Investments	3,370,222	1,020,339
Net Cash and Cash Equivalents Used by Investing Activities	(80,127)	(557,777)
<b>NET CHANGE IN CASH AND CASH EQUIVALENTS</b>	37,862	(7,756)
Cash and Cash Equivalents - Beginning of Year	734,683	742,439
<b>CASH AND CASH EQUIVALENTS - END OF YEAR</b>	\$ 772,545	\$ 734,683

See accompanying Notes to Financial Statements.

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**NOTES TO FINANCIAL STATEMENTS**  
**DECEMBER 31, 2022 AND 2021**

**NOTE 1 ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES**

**Nature of Operations**

National Foundation for Ectodermal Dysplasias (the Foundation) 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 – The Family Support Council, comprised of family members and affected individuals, oversees the Foundation’s support programs that seek to empower and connect individuals affected by ectodermal dysplasias and their families. The Foundation 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 the Foundation’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. The Foundation provides financial assistance to individuals to attend the Family Conference and academic scholarship for post-secondary education to recognize the achievements of our youth. The Foundation’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 – Medical and dental experts comprise the Patient Care Council which oversees the Foundation’s initiatives to improve treatment of ectodermal dysplasias. The Foundation teaches care providers how to diagnose and treat the rare disorders through professional symposia and Grand Rounds at universities. The Foundation 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 Foundation Dental Treatment Centers in the U.S. The Foundation also helps families pay for needed care through the Treatment Assistance Program and insurance coaching.

Research – The Scientific Advisory Council oversees the Foundation’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. The Foundation advances research through advocacy and partnerships with organizations such as the National Institutes of Health. The Foundation provides seed funds to researchers, provides them with access to affected individuals, and shares information to launch larger projects. The web-based Ectodermal Dysplasias International Registry serves as a repository of clinical information and facilitates communication among affected individuals, clinicians involved in their treatment, and scientists who strive to advance research on ectodermal dysplasias. The Foundation also sponsors scientific meetings to increase understanding of the disorders.

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**NOTES TO FINANCIAL STATEMENTS**  
**DECEMBER 31, 2022 AND 2021**

**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 the Foundation.

**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 the Foundation and/or the passage of time. Other net assets require that they be maintained in perpetuity by the Foundation. Generally, the donors of these assets permit the Foundation to use all or part of the income earned on related investments for specific purposes. The Foundation did not have net assets to be maintained in perpetuity at December 31, 2022 and 2021.

**Basis of Accounting**

The financial statements of the Foundation 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, 2022 AND 2021**

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

**Pledges**

The Foundation receives pledges in the form of grants and contributions. Pledges, including unconditional promises to give cash and other assets to the Foundation 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 the Foundation'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 the Foundation's various fundraising events. These items are recorded at estimated fair value, as determined by management, at the time of receipt.

**Tax Status**

The Foundation 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, 2022 AND 2021**

**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. The Foundation 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, the Foundation reports expirations of donor restrictions when the assets are placed in service. The Foundation 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.

The Foundation 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 the Foundation, but these services do not meet the criteria for recognition as donated services.

In-kind donations in 2022 balance consisted primarily of special events donations and board of directors' travel expenses, and office rent donated by the Foundation's landlord. In 2021, balance consisted primarily of special event donations, legal expenses, and office rent donated by the Foundation'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 December 2027.

**Functional Expenses**

The Foundation 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, 2022 AND 2021**

**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 the Foundation 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 the Foundation'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**

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

**Subsequent Events**

In preparing these financial statements, the Foundation has evaluated events and transactions for potential recognition or disclosure through March 30, 2023, the date the financial statements were available to be issued.

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**NOTES TO FINANCIAL STATEMENTS**  
**DECEMBER 31, 2022 AND 2021**

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

**Leases**

The Foundation leases office space, a copier, and a postage machine. The Foundation 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 the Foundation's right to use an underlying asset for the lease term and lease liabilities represent the Foundation'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, the Foundation 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 the Foundation will exercise that option. Lease expense for operating lease payments is recognized on a straight-line basis over the lease term. The Foundation 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.

The Foundation 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. The Foundation's lease agreements do not contain any material residual value guarantees or material restrictive covenants.

**Change in Accounting Principles**

In September 2020, the Financial Accounting Standards Board (FASB) issued Accounting Standards (ASU) 2020-07, *Not-for-Profit Entities (Topic 958): Presentation and Disclosures by Not-for-Profit Entities for Contributed Nonfinancial Assets*. This ASU was issued to improve the transparency of contributed nonfinancial assets through enhancements to presentation and disclosure. The amendment to this ASU requires Not-for-Profits to (1) present contributed nonfinancial assets as a separate line item in the statement of activities, apart from contributions of cash and other financial assets and (2) include a disclosure of the disaggregation of the amount of contributed nonfinancial assets recognized by category that depicts the type of contributed nonfinancial assets. No cumulative-effect adjustment in net assets was recorded as a result of the adoption.

In February 2016, the FASB issued Accounting Standards Update 2016-02, *Leases (ASC 842)*. The new standard increases transparency and comparability among organizations by requiring the recognition of right-of-use (ROU) assets and lease liabilities on the balance sheet. Most prominent of the changes in the standard is the recognition of ROU assets and lease liabilities by lessees for those leases classified as operating leases. Under the standard, disclosures are required to meet the objective of enabling users of financial statements to assess the amount, timing, and uncertainty of cash flows arising from leases.



**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**NOTES TO FINANCIAL STATEMENTS**  
**DECEMBER 31, 2022 AND 2021**

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

**Change in Accounting Principles (Continued)**

The Foundation adopted the requirements of the guidance effective January 1, 2022 and has elected to apply the provisions of this standard to the beginning of the period of adoption, through a cumulative effect adjustment, with certain practical expedients available. Lease disclosures for the year ended December 31, 2021 are made under prior lease guidance in FASB ASC 840.

The Foundation elected the available practical expedients to account for existing capital leases and operating leases as finance leases and operating leases, respectively, under the new guidance, without reassessing (a) whether the contracts contain leases under the new standard, (b) whether classification of capital leases or operating leases would be different in accordance with the new guidance, or (c) whether the unamortized initial direct costs before transition adjustments would have met the definition of initial direct costs in the new guidance at lease commencement.

**NOTE 2 PROPERTY AND EQUIPMENT**

Property and equipment consists of the following at December 31:

	<u>2022</u>	<u>2021</u>
Furnishings, Fixtures, and Equipment	\$ 41,323	\$ 41,323
Less: Accumulated Depreciation	<u>(41,323)</u>	<u>(41,323)</u>
Total Net of Depreciation	<u>\$ -</u>	<u>\$ -</u>

There was no depreciation expense for the years ended December 31, 2022 and 2021, respectively.

**NOTE 3 INVESTMENTS**

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

	<u>2022</u>	<u>2021</u>
Level 1 Assets:		
Stocks	\$ 1,155,685	\$ 115,873
Mutual Funds:	1,181,833	2,929,986
Exchange Traded Funds	705,899	479,291
Real Estate Index Funds	17,285	-
Total Level 1 Assets	<u>\$ 3,060,702</u>	<u>\$ 3,525,150</u>

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
**NOTES TO FINANCIAL STATEMENTS**  
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**NOTE 3 INVESTMENTS (CONTINUED)**

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

	2022	2021
Interest and Dividends	\$ 36,067	\$ 25,781
Realized Investment Gains	218,323	403,695
Unrealized Investment Gains (Losses)	(877,198)	56,683
Total	\$ (622,808)	\$ 486,159

**NOTE 4 PLEDGES RECEIVABLE**

Pledges receivable are due as follows:

	2022	2021
Due in Less Than One Year	\$ 4,389	\$ 4,389
Due in One to Five Years	17,186	21,574
Face Value of Pledges Receivable	\$ 21,575	\$ 25,963

**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:

	2022	2021
Cash and Equivalents	\$ 772,545	\$ 734,683
Investments	3,060,702	3,525,150
Financial Assets Available for Expenses	3,833,247	4,259,833
Purpose Restricted Expenses	(95,565)	(96,882)
Financial Assets Available to Meet Cash Needs for General Expenditures Within One Year	\$ 3,737,682	\$ 4,162,951

**NOTE 6 NET ASSETS WITH DONOR RESTRICTIONS**

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

	2022	2021
In-Kind Rent	\$ 21,572	\$ 25,961
Research Program	95,565	96,882
Total Net Assets with Donor Restrictions	\$ 117,137	\$ 122,843

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**NOTE 6 NET ASSETS WITH DONOR RESTRICTIONS (CONTNUED)**

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

	<u>2022</u>	<u>2021</u>
Research Program	\$ 20,694	\$ 18,581
In-Kind Rent	4,389	4,389
Total	<u>\$ 25,083</u>	<u>\$ 22,970</u>

**NOTE 7 TREATMENT AND RESEARCH COMMITMENTS**

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

	<u>2022</u>	
	<u>Treatment</u>	<u>Research</u>
Due in Less Than One Year	\$ 6,100	\$ -
Due in One to Five Years	-	-
Total	<u>\$ 6,100</u>	<u>\$ -</u>
	<u>2021</u>	
	<u>Treatment</u>	<u>Research</u>
Due in Less Than One Year	\$ 9,177	\$ -
Due in One to Five Years	-	-
Total	<u>\$ 9,177</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, 2022 or 2021.

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS**  
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**NOTE 8 LEASES – ASC 842**

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

The following table provides quantitative information concerning the Foundation’s leases as of and for the year ended December 31, 2022:

**Lease Costs:**

Operating Lease Costs	\$ 29,034
Total Building and Equipment Lease Costs	<u>\$ 29,034</u>

**Other Information:**

Cash Paid for Amounts Included in the Measurement of Lease Liabilities:	
Operating Cash Flows from Operating Leases	\$ 29,034
Weighted-Average Remaining Lease Term - Operating Leases	4.6 Years
Weighted-Average Discount Rate - Operating Leases	4.13%

The Foundation 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, 2022, is as follows:

<u>Year</u>	<u>Operating Leases</u>
2023	\$ 29,178
2024	29,178
2025	29,178
2026	25,944
2027	20,112
Total Lease Payments	<u>133,590</u>
Less: Interest	<u>(12,300)</u>
Total	<u>\$ 121,290</u>

**NOTE 9 OPERATING LEASES – ASC 840**

The Foundation elected to apply the provisions of FASB ASC 842 to the beginning of the period of adoption, through a cumulative effect adjustment, with certain practical expedients available. Lease disclosures for the year ended December 31, 2021 are made under prior lease guidance in FASB ASC 840.

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**NOTES TO FINANCIAL STATEMENTS**  
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**NOTE 9 OPERATING LEASES – ASC 840 (CONTINUED)**

The Foundation rents office space and certain office equipment under operating lease arrangements that expire at various dates through November 2027. Rent expense totaled \$28,296 for the year ended December 31, 2021. Future minimum lease payments at December 31, 2021 are as follows:

<u>Year Ending December 31,</u>	<u>Amount</u>
2022	\$ 29,032
2023	29,032
2024	29,032
2025	29,032
2026	27,133
Thereafter	22,634
Total	<u>\$ 165,895</u>

**NOTE 10 EMPLOYEE BENEFIT PLAN**

The Foundation provides a SIMPLE individual retirement plan to substantially all employees. At their discretion, the Foundation's board of directors may approve Foundation contributions to the Plan. In 2022 and 2021, contribution expenses totaled \$11,831 and \$11,680, respectively.

**NOTE 11 NONFINANCIAL CONTRIBUTIONS**

Donated goods and services of \$35,537 and \$12,452 have been reflected in the financial statements for the years ended December 31, 2022 and 2021 respectively, including items such as rent, apparel, and various auction items for special events. All donated items are used by the Foundation, not monetized, and did not have donor-imposed restrictions associated with them. The Foundation 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>2022</u>	<u>2021</u>
Board In-Kind	\$ 15,018	\$ 4,288
Special Event In-Kind	20,519	8,164
Total In-Kind	<u>\$ 35,537</u>	<u>\$ 12,452</u>



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