

**NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS**

FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2020 AND 2019

**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
TABLE OF CONTENTS
YEARS ENDED DECEMBER 31, 2020 AND 2019**

INDEPENDENT AUDITORS' REPORT	1
FINANCIAL STATEMENTS	
STATEMENTS OF FINANCIAL POSITION	3
STATEMENTS OF ACTIVITIES	4
STATEMENTS OF FUNCTIONAL EXPENSES	6
STATEMENTS OF CASH FLOWS	8
NOTES TO FINANCIAL STATEMENTS	9



INDEPENDENT AUDITORS' REPORT

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

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, 2020 and 2019, and the related statements of activities, functional expenses, and cash flows for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free of material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Board of Directors
National Foundation for Ectodermal Dysplasias

Opinion

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, 2020 and 2019, 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.

CliftonLarsonAllen LLP

CliftonLarsonAllen LLP

St. Louis, Missouri
March 8, 2021

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENTS OF FINANCIAL POSITION
DECEMBER 31, 2020 AND 2019

	2020	2019
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	\$ 742,439	\$ 803,183
Investments	2,390,866	1,871,907
Pledges Receivable	4,388	4,388
Prepaid Expenses and Other Assets	10,986	7,829
Total Current Assets	3,148,679	2,687,307
UNCONDITIONAL PLEDGES RECEIVABLE, Net of Current Portion	25,963	30,351
Total Assets	\$ 3,174,642	\$ 2,717,658
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable	\$ 794	\$ 11,961
Treatment Commitments	14,200	20,000
Accrued Expenses	31,094	20,395
Total Current Liabilities	46,088	52,356
Total Liabilities	46,088	52,356
NET ASSETS		
Without Donor Restriction	3,048,264	2,557,645
With Donor Restriction	80,290	107,657
Total Net Assets	3,128,554	2,665,302
Total Liabilities and Net Assets	\$ 3,174,642	\$ 2,717,658

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENT OF ACTIVITIES
YEAR ENDED DECEMBER 31, 2020

	Without Donor Restriction	With Donor Restriction	Total
PUBLIC SUPPORT AND REVENUE			
Contributions	\$ 793,549	\$ -	\$ 793,549
Fundraising Special Events	33,475	-	33,475
Sales of Publications/Promotional Items	207	-	207
In-Kind Donations - Board of Directors	3,981	-	3,981
In-Kind Donations - Other	36,782	-	36,782
Investment Income	303,019	-	303,019
Gain on Extinguishment	77,200	-	77,200
Net Assets Released from Restrictions	27,367	(27,367)	-
Total Public Support and Revenue	1,275,580	(27,367)	1,248,213
EXPENSES			
Program Services:			
Support	300,233	-	300,233
Treatment	175,739	-	175,739
Research	164,967	-	164,967
Supporting Services:			
Management and General	12,240	-	12,240
Fundraising	131,782	-	131,782
Total Expenses	784,961	-	784,961
NET CHANGE IN NET ASSETS	490,619	(27,367)	463,252
Net Assets - Beginning of Year	2,557,645	107,657	2,665,302
NET ASSETS - END OF YEAR	\$ 3,048,264	\$ 80,290	\$ 3,128,554

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENT OF ACTIVITIES
YEAR ENDED DECEMBER 31, 2019

	<u>Without Donor Restriction</u>	<u>With Donor Restriction</u>	<u>Total</u>
PUBLIC SUPPORT AND REVENUE			
Contributions	\$ 819,536	\$ 3,563	\$ 823,099
Fundraising Special Events	66,150	-	66,150
Less: Costs of Direct Benefits to Donors	-	-	-
Conference Registration Fees	59,185	-	59,185
Sales of Publications/Promotional Items	3,652	-	3,652
In-Kind Donations - Board of Directors	4,447	-	4,447
In-Kind Donations - Other	1,170	-	1,170
In-Kind Donations - Revenue for Fundraising Special Events	25,965	-	25,965
Investment Income	394,846	-	394,846
Net Assets Released from Restrictions	14,106	(14,106)	-
Total Public Support and Revenue	<u>1,389,057</u>	<u>(10,543)</u>	<u>1,378,514</u>
EXPENSES			
Program Services:			
Support	396,886	-	396,886
Treatment	159,932	-	159,932
Research	203,851	-	203,851
Supporting Services:			
Management and General	12,151	-	12,151
Fundraising	122,866	-	122,866
Total Expenses	<u>895,686</u>	<u>-</u>	<u>895,686</u>
NET CHANGE IN NET ASSETS	493,371	(10,543)	482,828
Net Assets - Beginning of Year	<u>2,064,274</u>	<u>118,200</u>	<u>2,182,474</u>
NET ASSETS - END OF YEAR	<u>\$ 2,557,645</u>	<u>\$ 107,657</u>	<u>\$ 2,665,302</u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED DECEMBER 31, 2020

	Program Services			Management and	Fundraising	Total
	Support	Treatment	Research	General		
Total Salaries and Related Expenses	\$ 181,856	\$ 122,497	\$ 100,805	\$ 5,834	\$ 86,069	\$ 497,061
Awareness	2,621	2,621	2,621	-	-	7,863
Board of Directors Expense	2,062	842	589	42	673	4,208
Client Assistance	-	(2,951)	-	-	-	(2,951)
Development	3,028	2,813	2,813	2,164	10,819	21,637
Family Conferences	6,755	-	-	-	-	6,755
Family Support Network	2,795	-	-	-	-	2,795
In-Kind - Professional and Other	14,821	9,881	9,881	823	5,764	41,170
Insurance	2,572	1,050	735	767	840	5,964
Marketing/Communications	13,868	5,548	4,161	555	3,606	27,738
Memberships	7,533	3,074	2,152	154	2,460	15,373
Miscellaneous	1,178	481	337	24	385	2,405
Office - General	4,905	1,960	1,372	99	1,568	9,904
Professional Fees	31,004	12,655	8,858	633	10,124	63,274
Program	20	20	21	-	-	29
Rent - Building	11,826	4,827	3,379	241	3,861	24,134
Repairs and Maintenance	425	174	121	9	139	868
Research Funding	-	-	17,420	-	-	17,420
Special Events	1,125	1,045	1,045	804	4,019	8,038
Advocacy	7,384	7,384	7,384	-	-	22,152
Utilities	4,455	1,818	1,273	91	1,455	9,092
Total Expenses	<u>\$ 300,233</u>	<u>\$ 175,739</u>	<u>\$ 164,967</u>	<u>\$ 12,240</u>	<u>\$ 131,782</u>	<u>\$ 784,961</u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED DECEMBER 31, 2019

	Program Services			Management and	Fundraising	Total
	Support	Treatment	Research	General		
Total Salaries and Related Expenses	\$ 156,232	\$ 96,189	\$ 92,156	\$ 5,651	\$ 47,489	\$ 397,717
Awareness	8	9	9	-	-	26
Board of Directors Expense	2,460	985	734	94	655	4,928
Client Assistance	-	10,738	-	-	-	10,738
Development	4,312	3,987	3,984	3,058	15,298	30,639
Family Conferences	131,697	-	-	-	-	131,697
Family Support Network	227	-	-	-	-	227
In-Kind - Professional and Other	2,343	1,562	1,562	130	911	6,509
In-Kind - Special Events	-	-	-	-	25,965	25,965
Insurance	2,789	1,139	797	57	911	5,693
Marketing/Communications	21,496	8,598	6,449	860	5,589	42,992
Memberships	5,134	2,095	1,467	105	1,673	10,474
Miscellaneous	509	206	146	13	157	1,028
Office - General	5,754	2,313	1,620	116	1,854	11,657
Professional Fees	36,771	15,009	10,506	751	12,007	75,044
Program	141	142	142	-	-	425
Rent - Building	11,826	4,827	3,379	241	3,861	24,134
Repairs and Maintenance	132	54	38	3	42	269
Research Funding	-	-	69,379	-	-	69,379
Special Events	1,363	1,265	1,265	973	4,866	9,732
Advocacy	8,829	8,829	8,829	-	-	26,487
Utilities	4,863	1,985	1,389	99	1,588	9,924
Total Expenses	<u>\$ 396,886</u>	<u>\$ 159,932</u>	<u>\$ 203,851</u>	<u>\$ 12,151</u>	<u>\$ 122,866</u>	<u>\$ 895,686</u>

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
STATEMENTS OF CASH FLOWS
YEARS ENDED DECEMBER 31, 2020 AND 2019

	2020	2019
CASH FLOWS FROM OPERATING ACTIVITIES		
Net Change in Net Assets	\$ 463,252	\$ 482,828
Adjustments to Reconcile Net Change in Net Assets to Cash and Cash Equivalents Provided by Operating Activities:		
Donated Investments	(121,512)	(20,417)
Proceeds from Sale of Donated Investments	-	3,021
Investment (Gain) Loss	(278,693)	(368,417)
(Increase) Decrease in:		
Pledges Receivable	4,388	4,389
Prepaid Expenses and Other Assets	(3,157)	32,536
Increase (Decrease) in:		
Accounts Payable	(11,167)	11,918
Commitments	(5,800)	7,000
Accrued Expenses	10,699	(100)
Net Cash and Cash Equivalents Provided by Operating Activities	58,010	152,758
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Investments	(319,363)	(22,710)
Proceeds from Sale of Investments	200,609	177,536
Net Cash and Cash Equivalents Provided (Used) by Investing Activities	(118,754)	154,826
NET CHANGE IN CASH AND CASH EQUIVALENTS	(60,744)	307,584
Cash and Cash Equivalents - Beginning of Year	803,183	495,599
CASH AND CASH EQUIVALENTS - END OF YEAR	\$ 742,439	\$ 803,183

See accompanying Notes to Financial Statements.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2020 AND 2019

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, 2020 AND 2019

**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, 2020 and 2019.

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, 2020 AND 2019

**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, 2020 AND 2019

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 2020 balance consisted primarily of special events donations and board of directors' travel expenses, and office rent donated by the Foundation's landlord. In 2019, 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.

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:

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2020 AND 2019

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

Fair Value Measurements (Continued)

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 8, 2021, the date the financial statements were available to be issued.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2020 AND 2019

NOTE 2 PROPERTY AND EQUIPMENT

Property and equipment consists of the following at December 31:

	2020	2019
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, 2020 and 2019, respectively.

NOTE 3 INVESTMENTS

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

	2020	2019
Level 1 Assets:		
Equity Securities:		
Financial Services	\$ 35,244	\$ 10,419
Technology	111,020	7,960
Communication Services	28,655	2,249
Total Equity Securities	<u>174,919</u>	<u>20,628</u>
Mutual Funds:		
Large Value	388,059	360,189
Large Blend	815,064	602,311
Mid-Cap Blend	266,088	247,630
World Stock	517,161	454,042
Total Mutual Funds	<u>1,986,372</u>	<u>1,664,172</u>
Exchange Traded Fund:		
Large Blend	229,573	187,107
Total Exchange Traded Fund	<u>229,575</u>	<u>187,107</u>
Total Level 1 Assets	<u>\$ 2,390,866</u>	<u>\$ 1,871,907</u>

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

	2020	2019
Interest and Dividends	\$ 24,326	\$ 26,429
Realized Investment Gains	74,899	109,928
Unrealized Investment Gains (Losses)	203,794	258,489
Total	<u>\$ 303,019</u>	<u>\$ 394,846</u>

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2020 AND 2019

NOTE 4 PLEDGES RECEIVABLE

Pledges receivable are due as follows:

	2020	2019
Due in Less Than One Year	\$ 4,388	\$ 4,388
Due in One to Five Years	25,963	30,351
Face Value of Pledges Receivable	<u>\$ 30,351</u>	<u>\$ 34,739</u>

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:

	2020	2019
Cash and Equivalents	\$ 742,439	\$ 803,183
Investments	2,390,866	1,871,907
Financial Assets Available for Expenses	3,133,305	2,675,090
Purpose Restricted Expenses	(49,940)	(72,918)
Financial Assets Available to Meet Cash Needs for General Expenditures Within One Year	<u>\$ 3,083,365</u>	<u>\$ 2,602,172</u>

NOTE 6 NET ASSETS WITH DONOR RESTRICTIONS

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

	2020	2019
Treatment Program	\$ -	\$ 3,621
In-Kind Rent	30,350	34,739
Research Program	49,940	65,734
Advocacy	-	3,563
Total Net Assets with Donor Restrictions	<u>\$ 80,290</u>	<u>\$ 107,657</u>

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

	2020	2019
Research Program	\$ 15,794	\$ 5,996
Treatment Program	3,621	3,721
Advocacy	3,563	-
In-Kind Rent	4,389	4,389
Total	<u>\$ 27,367</u>	<u>\$ 14,106</u>

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2020 AND 2019

NOTE 7 TREATMENT AND RESEARCH COMMITMENTS

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

	2020	
	Treatment	Research
Due in Less Than One Year	\$ 14,200	\$ -
Due in One to Five Years	-	-
Total	\$ 14,200	\$ -
	2019	
	Treatment	Research
Due in Less Than One Year	\$ 20,000	\$ -
Due in One to Five Years	-	-
Total	\$ 20,000	\$ -

Family conference scholarships are generally committed and expensed in the same fiscal year and did not have any outstanding commitments at December 31, 2020 or 2019.

NOTE 8 OPERATING LEASES

The Foundation rents office space and certain office equipment under operating lease arrangements that expire at various dates through November 2027. Rent expense totaled \$29,897 and \$29,897 for the years ended December 31, 2020 and 2019, respectively.

Future minimum lease payments at December 31, 2020 are as follows:

Year Ending December 31,	Amount
2021	\$ 27,394
2022	24,132
2023	24,132
2024	24,132
2024	24,132
Thereafter	46,253
Total	\$ 170,175

NOTE 9 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 2020 and 2019, contribution expenses totaled \$9,024 and \$8,456, respectively.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2020 AND 2019

NOTE 10 RISKS AND UNCERTAINTIES

In March of 2020, the World Health Organization declared the outbreak of the coronavirus (COVID-19) as a pandemic, which continues to spread throughout the United States. COVID-19 has caused a severe negative impact on the world economy and has contributed to significant declines and volatility in financial markets. The duration and impact of the COVID-19 pandemic, as well as the effectiveness of government and central bank responses, remains unclear at this time. It is not possible to reliably estimate the duration and severity of these consequences, as well as their impact on the financial position and results of the Foundation for future periods. The Foundation revised its 2020 Budget, reducing expenses and expected income. The Foundation also cancelled its National Family Conference to protect its families with rare disorders. Management is carefully monitoring the situation and evaluating its options as circumstances evolve.

April 15, 2020, the Foundation received a loan from Regions Bank in the amount of \$77,200 to fund payroll, rent, utilities, and interest on mortgages and existing debt through the Paycheck Protection Program (the PPP Loan). On December 1, 2020 the Foundation received notification from Regions bank that the PPP loan was paid in full.