



**THE UNITED LEUKODYSTROPHY  
FOUNDATION, INC.**

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FINANCIAL STATEMENTS AND  
INDEPENDENT AUDITOR'S REPORT

For the Year Ended December 31, 2018



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**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**  
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## INDEPENDENT AUDITOR'S REPORT

Board of Directors  
The United Leukodystrophy Foundation, Inc.

### Report on the Financial Statements

We have audited the accompanying financial statements of The United Leukodystrophy Foundation, Inc. (the Organization) (an Indiana not-for-profit organization), which comprise the statement of financial position as of December 31, 2018, and the related statements of activities, functional expenses, and cash flows for the year 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.

### Auditor's Responsibility

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

## **Opinion**

In our opinion, the financial statements referred to above present fairly, in all material respects the financial position of The United Leukodystrophy Foundation, Inc. as of December 31, 2018, and the changes in its net assets and its cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America.

## **Emphasis of Matter**

As discussed in Note 2 to the financial statements, the entity adopted new accounting guidance as issued by the Financial Accounting Standards Board under Financial Accounting Standards Update 2016-14, *Not-for-Profit Entities (Topic 958) - Presentation of Financial Statements of Not-for-Profit Entities*. Our opinion is not modified with respect to this matter.

## **Report on Supplementary Information**

Our audit was conducted for the purpose of forming an opinion on the financial statements as a whole. The supplementary information as listed on the table of contents is presented for purposes of additional analysis and is not a required part of the financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the financial statements. The information has been subjected to the auditing procedures applied in the audit of the financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the financial statements or to the financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the financial statements as a whole.

*Sikich LLP*

Naperville, Illinois  
June 6, 2019

**FINANCIAL STATEMENTS**



**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**

**STATEMENT OF FINANCIAL POSITION**

December 31, 2018

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<b>ASSETS</b>	
<b>CURRENT ASSETS</b>	
Cash and cash equivalents	\$ 63,861
Pledges receivable	2,111
Prepaid expenses	<u>5,954</u>
Total current assets	<u>71,926</u>
<b>OTHER ASSETS</b>	
Investments	<u>771,591</u>
Total other assets	<u>771,591</u>
<b>FIXED ASSETS</b>	
Office equipment	21,003
Less accumulated depreciation	<u>(19,008)</u>
Total fixed assets	<u>1,995</u>
<b>TOTAL ASSETS</b>	<u><u>\$ 845,512</u></u>
<b>LIABILITIES AND NET ASSETS</b>	
<b>CURRENT LIABILITIES</b>	
Accounts payable	\$ 668
Capital lease payable	1,430
Accrued liabilities	<u>1,200</u>
Total current liabilities	<u>3,298</u>
<b>NET ASSETS</b>	
Without donor restrictions	127,569
With donor restrictions	<u>714,645</u>
Total net assets	<u>842,214</u>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<u><u>\$ 845,512</u></u>

See accompanying notes to financial statements.

**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**

STATEMENT OF ACTIVITIES

For the Year Ended December 31, 2018

	<b>Without Donor Restrictions</b>	<b>With Donor Restrictions</b>	<b>Total</b>
<b>REVENUE</b>			
Public support			
General contributions	\$ 181,700	\$ 9,235	\$ 190,935
Conference fees	136,423	-	136,423
Research contributions	-	30,160	30,160
Memberships	18,090	-	18,090
Grants	10,000	-	10,000
Fundraising, net direct benefit to donor	12,833	-	12,833
Total public support	359,046	39,395	398,441
Other revenues and gains			
Realized gain on investments	-	9,199	9,199
Interest income, net	-	27,837	27,837
Net assets released from restrictions	80,395	(80,395)	-
Total revenue	439,441	(3,964)	435,477
<b>EXPENSES AND LOSSES</b>			
Functional expenses			
Program services	302,849	-	302,849
Management and general	39,071	-	39,071
Fundraising	23,322	-	23,322
Total functional expenses	365,242	-	365,242
Losses			
Unrealized loss on investments	-	87,317	87,317
Realized loss on time share	17,250	-	17,250
Total losses	17,250	87,317	104,567
Total expenses and losses	382,492	87,317	469,809
CHANGE IN NET ASSETS	56,949	(91,281)	(34,332)
NET ASSETS, BEGINNING OF YEAR	70,620	805,926	876,546
<b>NET ASSETS, END OF YEAR</b>	<b>\$ 127,569</b>	<b>\$ 714,645</b>	<b>\$ 842,214</b>

See accompanying notes to financial statements.

THE UNITED LEUKODYSTROPHY FOUNDATION, INC.

STATEMENT OF FUNCTIONAL EXPENSES

For the Year Ended December 31, 2018

	Program Services			Management and General	Fundraising	Direct Benefit to Donor	Total
	Education	Research	Total				
<b>SALARIES AND RELATED EXPENSES</b>							
Office salaries	\$ 71,236	\$ -	\$ 71,236	\$ 1,532	\$ 3,830	\$ -	\$ 76,598
Payroll taxes	6,850	-	6,850	117	293	-	7,260
Workers' compensation	868	-	868	-	-	-	868
Total salaries and related expenses	78,954	-	78,954	1,649	4,123	-	84,726
<b>PROGRAM EXPENSES</b>							
Bank fees	-	-	-	3,592	-	-	3,592
Depreciation	2,146	-	2,146	119	119	-	2,384
Dues, subscriptions, and filing fees	538	-	538	-	7,452	-	7,990
Gifts	-	-	-	281	-	-	281
Insurance	-	-	-	3,302	-	-	3,302
Miscellaneous	-	-	-	1,066	-	-	1,066
Postage	3,135	-	3,135	-	989	-	4,124
Printing and educational materials	4,805	-	4,805	-	1,201	-	6,006
Professional fees	1,551	-	1,551	26,367	3,102	-	31,020
Promotion and advertising	5,772	-	5,772	-	-	-	5,772
Supplies	5,045	-	5,045	593	297	-	5,935
Telephone	2,746	-	2,746	211	60	-	3,017
Total program expenses	25,738	-	25,738	35,531	13,220	-	74,489
<b>TECHNOLOGY</b>	13,426	-	13,426	746	746	-	14,918
<b>SPECIAL PROJECTS</b>							
Annual appeal	-	-	-	-	4,660	-	4,660
Benefit drawing and prizes	-	-	-	-	-	13,335	13,335
Newsletter	4,097	-	4,097	-	-	-	4,097
Research grant	-	66,000	66,000	-	-	-	66,000
Total special projects	4,097	66,000	70,097	-	4,660	13,335	88,092
<b>OCCUPANCY</b>							
Rent	30,733	-	30,733	734	367	-	31,834
Utilities	3,497	-	3,497	411	206	-	4,114
Total occupancy	34,230	-	34,230	1,145	573	-	35,948
<b>TRAVEL AND MEETING EXPENSES</b>							
Travel	32,411	-	32,411	-	-	-	32,411
Meals and entertainment	42,730	-	42,730	-	-	-	42,730
Other conference and meeting	5,263	-	5,263	-	-	-	5,263
Total travel and meeting expenses	80,404	-	80,404	-	-	-	80,404
<b>TOTAL FUNCTIONAL EXPENSES</b>	<b>\$ 236,849</b>	<b>\$ 66,000</b>	<b>\$ 302,849</b>	<b>\$ 39,071</b>	<b>\$ 23,322</b>	<b>\$ 13,335</b>	<b>\$ 378,577</b>

See accompanying notes to financial statements.



**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**

**STATEMENT OF CASH FLOWS**

For the Year Ended December 31, 2018

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**CASH FLOWS FROM OPERATING ACTIVITIES**

Change in net assets	\$	(34,332)
Adjustments to reconcile change in net assets to cash from operating activities		
Depreciation		2,384
Realized gain on investments		(9,199)
Realized loss on time share		17,250
Unrealized loss on investments		87,317
Changes in certain assets and liabilities		
Prepaid expenses		(1,051)
Accounts payable		57
Accrued liabilities		(1,968)
		<hr/>
Net cash from operating activities		60,458

**CASH FLOWS FROM INVESTING ACTIVITIES**

Proceeds from the sale of investments		197,124
Payments for the purchase of investments		(275,352)
		<hr/>
Net cash from investing activities		(78,228)

**CASH FLOWS FROM FINANCING ACTIVITIES**

Principal payments on capital lease		(1,820)
		<hr/>
Net cash from financing activities		(1,820)

NET DECREASE IN CASH AND CASH EQUIVALENTS (19,590)

CASH AND CASH EQUIVALENTS, BEGINNING OF YEAR 

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83,451

CASH AND CASH EQUIVALENTS, END OF YEAR 

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\$ 63,861

See accompanying notes to financial statements.

# THE UNITED LEUKODYSTROPHY FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS

December 31, 2018

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### 1. NATURE OF ACTIVITIES

The United Leukodystrophy Foundation, Inc. (the Organization) is an Indiana not-for-profit organization founded on June 15, 1982. The Organization provides the family service and research funding.

### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### Basis of Accounting

The accompanying financial statements have been prepared on the accrual basis in conformity with accounting principles generally accepted in the United States of America (USGAAP).

#### Basis of Presentation

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

#### Without Donor Restrictions

Net assets that are not subject to donor-imposed restrictions. Board designated net assets are earmarked for a specific project, but do not have donor-imposed restrictions.

#### With Donor Restrictions

Net assets subject to donor-imposed restrictions that either expire by passage of time, can be fulfilled and removed by actions of the Organization pursuant to those restrictions.

#### Cash and Cash Equivalents

For purposes of reporting cash flows, cash is defined as cash on hand, amounts held at financial institutions, and short-term highly liquid investments that are readily convertible to known amounts of cash. Investments with an original maturity of three months or less are considered short-term for these purposes.

**2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)**

Investments

Investments in marketable securities with readily determinable fair values and all investments in debt securities are reported at their fair values. Fair value is determined by reference to quoted market prices and other relevant information generated by market transactions. Unrealized and realized gains and losses are included in revenue and support in the statement of activities. Money market funds included in the investment portfolio are treated as cash equivalents and presented as investments on the statement of financial position. Investment income is reported net of external and direct internal investment expenses.

Fixed Assets

Fixed assets are stated at cost or fair value if contributed. Furniture and equipment is capitalized if the items have a cost of \$1,000 or more and a useful life when acquired of more than one year. Depreciation is recorded on the straight-line method over the following estimated useful lives of the assets:

	<u>Years</u>
Office equipment	5

Depreciation expense is \$2,384 for the year ended December 31, 2018.

Use of Estimates

The preparation of financial statements in conformity with USGAAP requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

Revenue Recognition

Donations, contributions, and grants including unconditional promises to give, are recognized as revenues in the period received. Contributions of assets other than cash are recorded at their estimated fair value at the date of donation. Conference fees and fundraising revenues are recognized as deferred revenue until the conference or event is held.



**2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)**

In-Kind Donations

Donated services are recognized at their estimated fair value when they create or enhance nonfinancial assets or they require specialized skills which would need to be purchased if they were not donated. The Organization receives donated services from a variety of unpaid volunteers assisting the Organization in its charitable purpose. No amounts have been recognized for these services in the statement of activities because the criteria for recognition have not been satisfied. Donated goods are recognized as a contribution at their estimated fair value when donated. The Organization received donations of goods valued at \$3,054 for the year ended December 31, 2018. These amounts are included in contributions revenue and allocated between the functional expense categories on the statement of activities.

Functional Allocation of Expenses

The financial statements report certain categories of expenses that are attributable to more than one program or supporting function. Therefore, these expenses require allocation on a reasonable basis that is consistently applied. The expenses that are allocated include depreciation, office, and occupancy, which are allocated on a square-footage basis as well as salaries and benefits, which are allocated on the basis of estimates of time and effort.

Income Taxes

The Organization is a not-for-profit organization that is exempt from federal and state income taxes under Section 501(c)(3) of the Internal Revenue Code and is classified as other than a private foundation.

New Accounting Standards

In May 2014, the Financial Accounting Standards Board (FASB) issued ASU No. 2014-09, *Revenue from Contracts with Customers*, as amended by ASU No. 2015-14, which supersedes or replaces nearly all USGAAP revenue recognition guidance. This standard establishes a new contract and control-based revenue recognition model, changes the basis for deciding when revenue is recognized over time or at a point in time, and will expand disclosures about revenue. ASU No. 2014-09, as amended, is effective for nonpublic companies for annual reporting periods beginning after December 15, 2018 and interim periods within the annual period beginning after December 15, 2019. Management is currently assessing the impact of this new standard.



**2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)**

In February 2016, FASB issued ASU No. 2016-02, *Leases (Topic 842)*, to increase the transparency and comparability about leases among entities. The new guidance requires lessees to recognize a lease liability and a corresponding lease asset for virtually all lease contracts. It also requires additional disclosures about leasing arrangements. ASU No. 2016-02 is effective for nonpublic entities for fiscal years beginning after December 15, 2019 and interim periods within fiscal years beginning after December 15, 2020. ASU No. 2016-02 originally specified a modified retrospective transition method which requires the Organization to initially apply the new leases standard at the beginning of the earliest period presented in the financial statements. In July 2018, FASB issued ASU No. 2018-11, *Leases (Topic 842): Targeted Improvements*, providing a second, optional transition method which allows the Organization to apply the new standard at the adoption date and recognize a cumulative-effect adjustment to the opening balance of retained earnings in the period of adoption. The Organization is currently assessing the impact of this new standard, including the two optional transition methods.

In August 2018, FASB issued ASU No. 2018-13, *Changes to the Disclosure Requirements for Fair Value Measurements*. This standard is intended to improve the effectiveness of disclosures in the notes to the financial statements and modify the disclosure requirements on fair value measurements in Topic 820, *Fair Value Measurements*. ASU No. 2018-13 is effective for fiscal years beginning after December 15, 2019, with early adoption permitted. The Organization has chosen to early adopt this ASU as of and for the year ended December 31, 2018.

FASB has issued ASU No. 2016-14, *Not-for-Profit Entities (Subtopic 958): Presentation of Financial Statements of Not-for-Profit Entities*. ASU No. 2016-14 is intended to simplify and improve current net asset classification requirements and the information presented in financial statements and notes about a not-for-profit organization's liquidity, financial performance, expense classifications, and cash flows. ASU No. 2016-14 is effective for fiscal years beginning after December 15, 2017 with early adoption permitted. The Organization has adopted this ASU as of and for the year ending December 31, 2018.

**3. LIQUIDITY AND AVAILABILITY**

The Organization receives contributions and promises to give with donor restrictions to be used in accordance with the associated purpose or time restriction. In addition, the Organization receives support without donor restrictions; such support has historically represented approximately over 90% of program funding needs and over 93% for the year ended December 31, 2018.

The Organization considers it appropriate that earnings from contributions with and without donor restrictions are for use in current programs which are ongoing, major, and central to its annual operations and are also available to meet cash needs for general expenditures. General expenditures include administrative and general expenses and fundraising expenses expected to be paid in the subsequent year. Annual operations are defined as activities occurring during the Organization's fiscal year.

**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**  
NOTES TO FINANCIAL STATEMENTS (Continued)

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**3. LIQUIDITY AND AVAILABILITY (Continued)**

The Organization manages its cash available to meet general expenditures with the following guiding principles:

- Operating within a prudent range of financial soundness and stability
- Maintaining adequate liquid assets

Financial assets available for general expenditure, that is without donor or other restrictions limiting their use, within one year of the statement of position date, are comprised of the following:

FINANCIAL ASSETS	
Cash	\$ 63,861
Pledges receivable	<u>2,111</u>
Total financial assets available within one year	65,972
Less noncash pledges receivable	<u>(2,111)</u>
FINANCIAL ASSETS AVAILABLE TO MEET CASH NEEDS FOR GENERAL USE WITHIN ONE YEAR	
	<u>\$ 63,861</u>

Disbursements from investments are at the discretion of management of the Organization. There were no distributions during the year ended of December 31, 2018.

**4. FAIR VALUE MEASUREMENTS**

USGAAP establishes a framework for measuring fair value. That framework uses a hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. USGAAP requires the Organization to maximize the use of observable inputs when measuring fair value. The hierarchy describes three levels of inputs, which are as follows:

- Level 1: Quotes prices in active markets for identical assets or liabilities.
- Level 2: Quotes prices for similar assets or liabilities in active markets; quoted prices for identical assets or liabilities in inactive markets; or inputs that are derived principally from or corroborated by observable market data by correlation or other means.
- Level 3: Significant unobservable inputs.



**4. FAIR VALUE MEASUREMENTS (Continued)**

In many cases, a valuation technique used to measure fair value includes inputs from more than one level of the fair value hierarchy. The lowest level of significant input determines the placement of the entire fair value measurement in the hierarchy. The categorization of an investment within the hierarchy reflects the relative ability to observe the fair value measure and does not necessarily correspond to the perceived risk of that investment.

If an investment that is measured using net asset value (NAV) has a readily determinable fair value (that is, it can be traded on the measurement date at its published NAV), it is included in Level 1 of the hierarchy. Otherwise, investments measured using NAV's are not included in Level 1, 2, or 3, but are separately reported.

Valuation Techniques

Following is a description of the valuation techniques used for assets measured at fair value on a recurring basis. There have been no changes to the techniques used during the year ended December 31, 2018.

Mutual funds: Valued at the NAV of shares on the last trading day of the fiscal year.

At December 31, 2018, investments are stated at fair value and consist primarily of mutual funds as follows:

	Level 1		
	Program Services Account	Research Account	Total
Mutual funds			
Fixed income	\$ 97,732	\$ 256,269	\$ 354,001
Equities	83,587	231,730	315,317
Alternative	22,246	59,517	81,763
Total assets at fair value	\$ 203,565	\$ 547,516	751,081
Cash equivalents at cost			20,510
<b>TOTAL INVESTMENTS</b>			<b>\$ 771,591</b>

There are no Level 2 or Level 3 investments for the year ended December 31, 2018.

**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**  
NOTES TO FINANCIAL STATEMENTS (Continued)

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**5. CAPITAL LEASE PAYABLE**

The Organization leases equipment under a capital lease that expires November 15, 2019. The asset and liability under the capital lease is recorded at the lower of the present value of the minimum lease payments or the fair value of the asset. The asset is depreciated on a straight-line basis over the lower of its related lease terms or its estimated productive life. The portion of depreciation expense for the year ended December 31, 2018 attributable to the lease obligation equipment is \$1,560.

Minimum future lease payments under the capital lease as of December 31, 2018 are as follows:

Year ended December 31, 2019	\$ 1,430
Less: Amount representing interest	<u>-</u>
PRESENT VALUE OF NET MINIMUM LEASE PAYMENTS	<u>\$ 1,430</u>

**6. NET ASSETS WITH DONOR RESTRICTIONS**

Net assets with donor restrictions are restricted for the following purpose at December 31, 2018:

Program endowment	\$ 151,034
Research and grants endowment	<u>563,611</u>
TOTAL NET ASSETS WITH DONOR RESTRICTIONS	<u>\$ 714,645</u>

**7. ENDOWMENT**

The Organization's endowment consists of consist of two endowment funds established to support education and research programs. The endowment includes both donor-restricted endowment funds and funds designated by the Board of Directors to function as endowments (board-designated endowment funds). As required by USGAAP, net assets associated with endowment funds, including board-designated endowment funds, are classified and reported based on the existence or absence of donor-imposed restrictions.

The Organization's Board of Directors has interpreted the Uniform Prudent Management of Institutional Funds Act (UPMIFA) as requiring preservation of the fair value of the original gift as of the gift date of the donor-restricted endowment funds absent explicit donor stipulations to the contrary. As a result of this interpretation, the Organization classifies as permanently restricted net assets (a) the original value of gifts donated to the permanent endowment, (b) the original value of subsequent gifts to the permanent endowment, and



**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**  
**NOTES TO FINANCIAL STATEMENTS (Continued)**

**7. ENDOWMENT (Continued)**

(c) accumulations to the permanent endowment made in accordance with the direction of the applicable donor gift instrument at the time the accumulation is added to the fund. The remaining portion of donor-restricted endowment funds is classified as temporarily restricted net assets until those amounts are appropriated for expenditure by the Organization in a manner consistent with the standard of prudence prescribed by UPMIFA. In accordance with UPMIFA, the Organization considers the following factors in making a determination to appropriate or accumulate donor-restricted endowment funds:

1. Duration and preservation of the fund
2. Purposes of the Organization and the fund
3. General economic conditions
4. Possible effect of inflation and deflation
5. Expected total return from investment income and appreciation or depreciation of investments
6. Other resources of the Organization
7. Investment policies of the Organization

The composition of net assets by type of endowment fund at December 31, 2018, was:

	Without Donor Restrictions	With Donor Restrictions	Total
Board-designated endowment funds	\$ 56,946	\$ -	\$ 56,946
Donor-restricted endowment funds			
Donor-restricted gifts	-	214,645	214,645
Original donor-restricted gift amounts required to be maintained in perpetuity by donor	-	500,000	500,000
<b>TOTAL ENDOWMENT FUNDS</b>	<b>\$ 56,946</b>	<b>\$ 714,645</b>	<b>\$ 771,591</b>

The Organization's Board of Directors has designated investment funds be set aside for board approved funding conference expenses for future years.



**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**  
**NOTES TO FINANCIAL STATEMENTS (Continued)**

**7. ENDOWMENT (Continued)**

Changes in endowment net assets for the year ended December 31, 2018 were:

	Without Donor Restrictions	With Donor Restrictions	Total
ENDOWMENT NET ASSETS, BEGINNING OF YEAR	\$ -	\$ 805,926	\$ 805,926
Investment return			
Net interest and dividend income	-	27,837	27,837
Net appreciation, realized and unrealized	-	(78,118)	(78,118)
Contributions	-	25,000	25,000
Board designation to move contributions to endowment	56,946	-	56,946
Appropriation of endowment assets for expenditure	-	(66,000)	(66,000)
ENDOWMENT NET ASSETS, END OF YEAR	<u>\$ 56,946</u>	<u>\$ 714,645</u>	<u>\$ 771,591</u>

From time-to-time, the fair value of assets associated with individual donor-restricted endowment funds may fall below the level the Organization is required to retain as a fund of perpetual duration pursuant to donor stipulation or UPMIFA. Such endowments are often referred to as “underwater” endowments. Though the Organization is not required by donor-imposed restriction or law to use its unrestricted resources to restore the endowments to their historic dollar value, accounting guidance for not-for-profit organization require that such losses and subsequent gains be reflected as changes in unrestricted net assets until the fair values again reach their historical dollar values. In accordance with USGAAP, deficiencies of this nature are reported in unrestricted net assets. There were no such deficiencies at December 31, 2018.

The Organization has adopted investment and spending policies for endowment assets that attempt to provide a predictable stream of funding to programs and other items supported by its endowment while seeking to maintain the purchasing power of the endowment. Endowment assets include those assets of donor-restricted endowment funds the Organization must hold in perpetuity or for donor-specified periods, as well as those of board-designated endowment funds. Under the Organization’s policies, endowment assets are invested in a manner that is intended to produce the highest level of return while assuming a moderate level of investment risk. The Organization expects its endowment funds to provide an average rate of return of approximately 8% annually over time. Actual returns in any given year may vary from this amount.

**7. ENDOWMENT (Continued)**

To satisfy its long-term rate of return objectives, the Organization relies on a total return strategy in which investment returns are achieved through both current yield (investment income such as dividends and interest) and capital appreciation (both realized and unrealized). The Organization targets a diversified asset allocation that places a greater emphasis on equity-based investments to achieve its long-term return objectives within prudent risk constraints.

The Organization has a policy (the spending policy) of appropriating for expenditure each year 10% of its endowment fund's average fair value over the prior 12 quarters through the year end preceding the year in which expenditure is planned. This distribution is intended to support operations as well as cover investment-related fees and expenses. In establishing this policy, the Organization considered the long-term expected return on its endowment. This is consistent with the Organization's objective to maintain the purchasing power of endowment assets held in perpetuity or for a specified term, as well as to provide additional real growth through new gifts and investment return.

**8. LEASE COMMITMENT**

The Organization leases its office space under an operating lease with monthly rent of \$667 that expires July 8, 2019. The Organization also rents event space for conferences under short-term rental agreements. Rent expense is \$31,834 for the year ended December 31, 2018.

Future maturities rental payments are as follows:

<u>Year Ending</u> <u>December 31,</u>	
2019	<u>\$ 4,002</u>

**9. SUBSEQUENT EVENTS**

The Organization has been evaluated for subsequent events through June 6, 2019, the date on which the financial statements were available to be issued, and determined that there were no significant nonrecognized subsequent events through that date.

**SUPPLEMENTARY INFORMATION**



**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**

**SCHEDULE OF PUBLIC SUPPORT**

For the Year Ended December 31, 2018

	<b>Without Donor Restrictions</b>	<b>With Donor Restrictions</b>	<b>Total</b>
<b>GENERAL CONTRIBUTIONS</b>			
Contributions	\$ 83,822	\$ 9,235	\$ 93,057
Memorials	52,980	-	52,980
Outside fundraiser	44,898	-	44,898
<b>Total general contributions</b>	<b>181,700</b>	<b>9,235</b>	<b>190,935</b>
<b>CONFERENCES</b>			
National conference fees	10,615	-	10,615
Sponsorships and exhibitors	120,000	-	120,000
Auction	5,808	-	5,808
<b>Total conferences</b>	<b>136,423</b>	<b>-</b>	<b>136,423</b>
<b>RESEARCH CONTRIBUTIONS</b>			
Alexander's Disease programs	-	125	125
ALD/AMN programs	-	28,205	28,205
CTX research programs	-	250	250
Globoid Cell Krabbes program	-	1,400	1,400
Metachromatic programs	-	80	80
Pelizaeus-Merzbacher programs	-	100	100
<b>Total research contributions</b>	<b>-</b>	<b>30,160</b>	<b>30,160</b>
<b>MEMBERSHIPS</b>			
Family	16,410	-	16,410
Professional	1,680	-	1,680
<b>Total memberships</b>	<b>18,090</b>	<b>-</b>	<b>18,090</b>
<b>GRANTS</b>	<b>10,000</b>	<b>-</b>	<b>10,000</b>
<b>FUNDRAISING</b>			
Miscellaneous	2,088	-	2,088
Benefit drawing	10,745	-	10,745
<b>Total fundraising</b>	<b>12,833</b>	<b>-</b>	<b>12,833</b>
<b>TOTAL PUBLIC SUPPORT</b>	<b>\$ 359,046</b>	<b>\$ 39,395</b>	<b>\$ 398,441</b>