

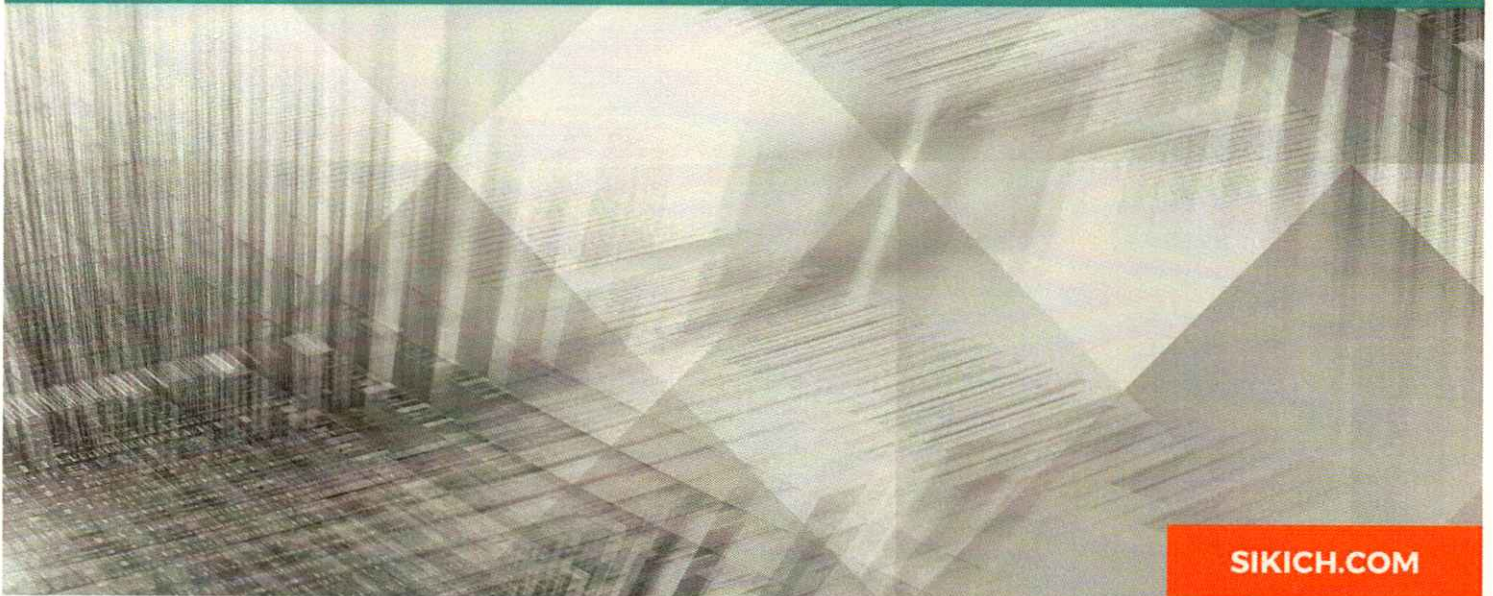


**THE UNITED LEUKODYSTROPHY  
FOUNDATION, INC.**

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FINANCIAL STATEMENTS AND  
INDEPENDENT AUDITOR'S REPORT

For the Years Ended December 31, 2019 and 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 statements of financial position as of December 31, 2019 and 2018, 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.

### **Auditor's 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 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, 2019 and 2018, and the changes in its net assets and its cash flows for the years 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 Organization adopted the provisions of Accounting Standards Update (ASU) No. 2014-09, *Revenue from Contracts with Customers*, as amended by ASU No. 2015-14, which supersedes or replaces nearly all accounting principles generally accepted in the United States of America revenue recognition guidance. The adoption of this ASU did not result in a change to the accounting for any of the Organization's revenue streams; as such, no cumulative effect adjustment was recorded. Our opinion is not modified with respect to this matter.

## **Report on Supplementary Information**

Our audits were 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  
April 23, 2020

**FINANCIAL STATEMENTS**

**THE UNITED LEUKODYSTROPHY FOUNDATION, INC.**

**STATEMENTS OF FINANCIAL POSITION**

December 31, 2019 and 2018

	<u>2019</u>	<u>2018</u>
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	\$ 102,499	\$ 63,861
Pledges receivable	-	2,111
Prepaid expenses	2,748	5,954
Total current assets	<u>105,247</u>	<u>71,926</u>
<b>OTHER ASSETS</b>		
Investments	<u>833,526</u>	<u>771,591</u>
Office equipment	21,003	21,003
Less accumulated depreciation	<u>20,684</u>	<u>19,008</u>
Total fixed assets	<u>319</u>	<u>1,995</u>
<b>TOTAL ASSETS</b>	<u><u>\$ 939,092</u></u>	<u><u>\$ 845,512</u></u>
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable	\$ 7,138	\$ 668
Capital lease payable	-	1,430
Accrued liabilities	1,791	1,200
Total current liabilities	<u>8,929</u>	<u>3,298</u>
<b>NET ASSETS</b>		
Without donor restrictions	207,165	127,569
With donor restrictions	<u>722,998</u>	<u>714,645</u>
Total net assets	<u>930,163</u>	<u>842,214</u>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<u><u>\$ 939,092</u></u>	<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, 2019

	<b>Without Donor Restrictions</b>	<b>With Donor Restrictions</b>	<b>Total</b>
<b>REVENUE</b>			
Public support			
Contributions	\$ 147,659	\$ -	\$ 147,659
Conference fees	189,004	-	189,004
Research contributions	-	34,378	34,378
Memberships	20,025	-	20,025
Fundraising, net direct benefit to donor	14,640	-	14,640
Interest income, net	6,087	15,982	22,069
Total public support	377,415	50,360	427,775
Net assets released from restrictions	111,049	(111,049)	-
Total revenue	488,464	(60,689)	427,775
<b>EXPENSES</b>			
Functional expenses			
Program services	345,165	-	345,165
Management and general	64,883	-	64,883
Fundraising	24,265	-	24,265
Total functional expenses	434,313	-	434,313
Change in net assets before investment activity	54,151	(60,689)	(6,538)
Net appreciation on investments	25,445	69,042	94,487
<b>CHANGE IN NET ASSETS</b>	79,596	8,353	87,949
<b>NET ASSETS, BEGINNING OF YEAR</b>	127,569	714,645	842,214
<b>NET ASSETS, END OF YEAR</b>	\$ 207,165	\$ 722,998	\$ 930,163

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			
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
Interest income, net	-	27,837	27,837
Total public support	<u>359,046</u>	<u>67,232</u>	<u>426,278</u>
Net assets released from restrictions	<u>80,395</u>	<u>(80,395)</u>	<u>-</u>
Total revenue	<u>439,441</u>	<u>(13,163)</u>	<u>426,278</u>
<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	<u>365,242</u>	<u>-</u>	<u>365,242</u>
Losses			
Net depreciation on investments	-	78,118	78,118
Realized loss on time share	17,250	-	17,250
Total losses	<u>17,250</u>	<u>78,118</u>	<u>95,368</u>
Total expenses and losses	<u>382,492</u>	<u>78,118</u>	<u>460,610</u>
CHANGE IN NET ASSETS	56,949	(91,281)	(34,332)
NET ASSETS, BEGINNING OF YEAR	<u>70,620</u>	<u>805,926</u>	<u>876,546</u>
NET ASSETS, END OF YEAR	<u>\$ 127,569</u>	<u>\$ 714,645</u>	<u>\$ 842,214</u>

See accompanying notes to financial statements.



THE UNITED LEUKODYSTROPHY FOUNDATION, INC.

STATEMENT OF FUNCTIONAL EXPENSES

For the Year Ended December 31, 2019

	Program Services			Management and General	Fundraising	Direct Benefit to Donor	Total
	Education	Research	Total				
<b>SALARIES AND RELATED EXPENSES</b>							
Office salaries	\$ 46,351	\$ -	\$ 46,351	\$ 997	\$ 2,492	\$ -	\$ 49,840
Payroll taxes	4,310	-	4,310	93	232	-	4,635
Workers' compensation	536	-	536	-	-	-	536
Total salaries and related expenses	51,197	-	51,197	1,090	2,724	-	55,011
<b>PROGRAM EXPENSES</b>							
Bank fees	-	-	-	3,139	-	-	3,139
Depreciation	1,508	-	1,508	84	84	-	1,676
Dues, subscriptions, and filing fees	2,928	-	2,928	-	2,928	-	5,856
Gifts	-	-	-	185	-	-	185
Insurance	-	-	-	6,168	-	-	6,168
Miscellaneous	-	-	-	575	-	-	575
Postage	3,208	-	3,208	-	2,855	-	6,063
Printing and educational materials	2,558	-	2,558	-	6,370	-	8,928
Professional fees	2,695	-	2,695	45,821	5,391	-	53,907
Promotion and advertising	-	-	-	1,000	-	-	1,000
Supplies	5,044	-	5,044	593	297	-	5,934
Telephone	2,834	-	2,834	218	62	-	3,114
Total program expenses	20,775	-	20,775	57,783	17,987	-	96,545
<b>TECHNOLOGY</b>	19,777	-	19,777	1,099	1,099	-	21,975
<b>SPECIAL PROJECTS</b>							
Benefit drawing and prizes	-	-	-	-	-	12,500	12,500
Newsletter	4,213	-	4,213	-	-	-	4,213
Research grant	-	89,671	89,671	-	-	-	89,671
Total special projects	4,213	89,671	93,884	-	-	12,500	106,384
<b>OCCUPANCY</b>							
Rent	40,566	-	40,566	4,773	2,386	-	47,725
Utilities	1,174	-	1,174	138	69	-	1,381
Total occupancy	41,740	-	41,740	4,911	2,455	-	49,106
<b>TRAVEL AND MEETING EXPENSES</b>							
Travel	37,655	-	37,655	-	-	-	37,655
Meals and entertainment	69,148	-	69,148	-	-	-	69,148
Other conference and meeting	10,989	-	10,989	-	-	-	10,989
Total travel and meeting expenses	117,792	-	117,792	-	-	-	117,792
<b>TOTAL FUNCTIONAL EXPENSES</b>	<b>\$ 255,494</b>	<b>\$ 89,671</b>	<b>\$ 345,165</b>	<b>\$ 64,883</b>	<b>\$ 24,265</b>	<b>\$ 12,500</b>	<b>\$ 446,813</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	-	2,641	-	5,776
Printing and educational materials	4,805	-	4,805	-	4,209	-	9,014
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	17,880	-	79,149
<b>TECHNOLOGY</b>	13,426	-	13,426	746	746	-	14,918
<b>SPECIAL PROJECTS</b>							
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	-	-	13,335	83,432
<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.**

STATEMENTS OF CASH FLOWS

For the Year Ended December 31, 2019

	2019	2018
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Change in net assets	\$ 87,949	\$ (34,332)
Adjustments to reconcile change in net assets to cash from operating activities		
Depreciation	1,676	2,384
Realized loss on time share	-	17,250
Net (appreciation) depreciation on investments	(94,487)	78,118
Changes in certain assets and liabilities		
Accounts receivable	2,111	-
Prepaid expenses	3,206	(1,051)
Accounts payable	6,469	57
Accrued liabilities	591	(1,968)
	<u>7,515</u>	<u>60,458</u>
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Proceeds from the sale of investments	274,933	197,124
Payments for the purchase of investments	<u>(242,380)</u>	<u>(275,352)</u>
	<u>32,553</u>	<u>(78,228)</u>
<b>CASH FLOWS FROM FINANCING ACTIVITIES</b>		
Principal payments on capital lease	<u>(1,430)</u>	<u>(1,820)</u>
	<u>(1,430)</u>	<u>(1,820)</u>
<b>NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS</b>	38,638	(19,590)
<b>CASH AND CASH EQUIVALENTS, BEGINNING OF YEAR</b>	<u>63,861</u>	<u>83,451</u>
<b>CASH AND CASH EQUIVALENTS, END OF YEAR</b>	<u>\$ 102,499</u>	<u>\$ 63,861</u>

See accompanying notes to financial statements.

# THE UNITED LEUKODYSTROPHY FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS

For the Years Ended December 31, 2019 and 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 \$1,676 and \$2,384 for the years ended December 31, 2019 and 2018, respectively.

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

*Adoption of New Accounting Standard*

The Financial Accounting Standards Board (FASB) issued new guidance that created Topic 606, *Revenue from Contracts with Customers*, in the Accounting Standards Codification (ASC). Topic 606 supersedes the revenue recognition requirements in FASB ASC 605, *Revenue Recognition*, and requires the recognition of revenue when promised services are transferred to customers in an amount that reflects the consideration to which an entity expects to be entitled in exchange for those services.

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

Revenue Recognition (Continued)

*Adoption of New Accounting Standard (Continued)*

The Organization adopted the requirement of Topic 606 as of January 1, 2019, utilizing the modified retrospective method of transition. The new guidance was applied using the practical expedient provided in Topic 606 that allows guidance to be applied only to contracts that were not complete as of January 1, 2019. The adoption of this new accounting pronouncement did not have a material impact on the financial statements.

The Organization's revenue is derived from the following sources:

*Contributions:* Contributions, including unconditional promises to give, are recognized as revenues in the period the promise is received. Conditional promises to give are not recognized until the conditions on which they depend are substantially met and are reported as with donor restrictions. Contribution that are restricted by the donor is reported as an increase in net assets without donor restrictions, if the restriction expires in the reporting period in which the contribution is earned. None of these contributions are considered to be exchange transactions and therefore, do not fall under Topic 606.

*Conferences fees:* The Organization hosts an annual conference with medical professionals for families to participate in educational seminars about leukodystrophy. The performance obligation is the delivery of the event and the price event fee is set by the Institute. Revenues from conferences are recognized at the time of the associated event.

FASB has issued Accounting Standards Update (ASU) No. 2018-08, *Not-for-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made*. ASU No. 2018-08 is intended to assist entities in (1) evaluating whether transactions should be accounted for as contributions (nonreciprocal transactions) within the scope of contribution accounting guidance, or as exchange (reciprocal) transactions subject to other guidance, and (2) determining whether a contribution is conditional. ASU No. 2018-08 is effective for fiscal years beginning after December 15, 2018, for transactions in which the entity serves as a resource recipient, and for fiscal years beginning after December 15, 2019, for transactions in which the entity serves as a resource provider. The Organization implemented this standard during the fiscal year ended December 31, 2019. The adoption of ASU No. 2018-08 did not result in a change to the accounting for any of the revenue streams and did not have a material impact on the financial statements.

**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 \$3,384 and \$3,054 for the years ended December 31, 2019 and 2018, respectively. These amounts are included in contribution 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 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 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, as amended by ASU No. 2019-10, is effective for nonpublic entities for fiscal years beginning after December 15, 2020 and interim periods within fiscal years beginning after December 15, 2021. ASU No. 2016-02 originally specified a modified retrospective transition method which requires the entity 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 entity 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 Foundation is currently assessing the impact of this new standard, including the two optional transition methods.

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

**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 84% for the year ended December 31, 2019.

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 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:

	2019	2018
Cash	\$ 102,499	\$ 63,861
Investments	833,526	771,591
Pledges receivable	-	2,111
	<hr/>	<hr/>
Total financial assets available within one year	936,025	837,563
Noncash pledges receivable	-	(2,111)
Net assets with donor restriction	(722,998)	(714,645)
Net assets with board designations	(110,528)	(56,946)
	<hr/>	<hr/>
<b>FINANCIAL ASSETS AVAILABLE TO MEET CASH NEEDS FOR GENERAL USE WITHIN ONE YEAR</b>	<b>\$ 102,499</b>	<b>\$ 63,861</b>

Disbursements from investments are at the discretion of management of the Organization. There were no distributions during the year ended of December 31, 2019.



#### **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.

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 years ended December 31, 2019 and 2018.

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

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

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

At December 31, 2019, 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	\$ 113,902	\$ 282,180	\$ 396,082
Equities	99,017	245,617	344,634
Alternative	20,697	51,272	71,969
	<hr/>		
Total assets at fair value	\$ 233,616	\$ 579,069	812,685
	<hr/>		
Cash equivalents at cost			20,841
	<hr/>		
TOTAL INVESTMENTS			\$ 833,526

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
	<hr/>		
Total assets at fair value	\$ 203,565	\$ 547,516	751,081
	<hr/>		
Cash equivalents at cost			20,510
	<hr/>		
TOTAL INVESTMENTS			\$ 771,591

There are no Level 2 or Level 3 investments for the year ended December 31, 2019 and 2018.

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

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**5. CAPITAL LEASE PAYABLE**

The Organization leased equipment under a capital lease that expired 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 years ended December 31, 2019 and 2018 attributable to the lease obligation equipment is \$1,170 and \$1,560, respectively.

**6. NET ASSETS WITH DONOR RESTRICTIONS**

Net assets with donor restrictions are restricted for the following purpose at December 31, 2019 and 2018:

	2019	2018
Program endowment	\$ 129,654	\$ 151,034
Research and grants endowment	593,344	563,611
<b>TOTAL NET ASSETS WITH DONOR RESTRICTIONS</b>	<b>\$ 722,998</b>	<b>\$ 714,645</b>

**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 with donor restricted net assets (a) the original value of gifts donated to the donor restricted endowment, (b) the original value of subsequent gifts to the donor restricted endowment, and (c) accumulations to the donor restricted 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 with donor restricted net assets for time or for purpose, until those amounts are appropriated for expenditure by the Organization in a manner consistent with the standard of prudence prescribed by UPMIFA.

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

**7. ENDOWMENT (Continued)**

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, 2019, was:

	Without Donor Restrictions	With Donor Restrictions	Total
Board-designated endowment funds	\$ 110,528	\$ -	\$ 112,230
Donor-restricted endowment funds			
Donor-restricted gifts	-	222,998	221,296
Original donor-restricted gift amounts required to be maintained in perpetuity by donor	-	500,000	500,000
<b>TOTAL ENDOWMENT FUNDS</b>	<b>\$ 110,528</b>	<b>\$ 722,998</b>	<b>\$ 833,526</b>

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, 2019 were:

	Without Donor Restrictions	With Donor Restrictions	Total
ENDOWMENT NET ASSETS, BEGINNING OF YEAR	\$ 56,946	\$ 714,645	\$ 771,591
Investment return			
Net interest and dividend income	6,087	15,982	22,069
Net appreciation, realized and unrealized	25,445	69,042	94,487
Contributions	-	34,378	34,378
Board designation to move contributions to endowment	22,050	-	22,050
Appropriation of endowment assets for expenditure	-	(111,049)	(111,049)
ENDOWMENT NET ASSETS, END OF YEAR	<u>\$ 110,528</u>	<u>\$ 722,998</u>	<u>\$ 833,526</u>

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 depreciation, realized and unrealized	-	(78,118)	(78,118)
Contributions	-	39,395	39,395
Board designation to move contributions to endowment	56,946	-	56,946
Appropriation of endowment assets for expenditure	-	(80,395)	(80,395)
ENDOWMENT NET ASSETS, END OF YEAR	<u>\$ 56,946</u>	<u>\$ 714,645</u>	<u>\$ 771,591</u>

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

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**7. ENDOWMENT (Continued)**

From time to time, the fair value of assets associated with donor restricted endowment funds may fall below the level that the donor or state law requires the Organization to retain as a fund of perpetual duration. There were no such deficiencies as of December 31, 2019 or 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.

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, 2020. The Organization also rents event space for conferences under short-term rental agreements. Rent expense is \$47,725 and \$31,834 for the years ended December 31, 2019 and 2018, respectively.

Future maturities rental payments are as follows:

<u>Year Ending</u> <u>December 31,</u>	
2020	<u>\$ 4,002</u>

**9. SUBSEQUENT EVENTS**

Beginning around March 2020, The Covid-19 virus has been declared a global pandemic as it continues to spread rapidly. As a result, equity investments of the Plan have experienced significant declines in quoted prices on active markets. Management of the Plan is carefully monitoring the situation and evaluating its options during this time. No adjustments have been made to these financial statements as a result of this uncertainty.

The Organization has been evaluated for subsequent events through April 23, 2020, 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, 2019

	<b>Without Donor Restrictions</b>	<b>With Donor Restrictions</b>	<b>Total</b>
<b>GENERAL CONTRIBUTIONS</b>			
Contributions	\$ 98,488	\$ -	\$ 98,488
Memorials	35,207	-	35,207
Outside fundraiser	13,964	-	13,964
Total general contributions	147,659	-	147,659
<b>CONFERENCES</b>			
National conference fees	9,125	-	9,125
Sponsorships and exhibitors	174,927	-	174,927
Auction	4,952	-	4,952
Total conferences	189,004	-	189,004
<b>RESEARCH CONTRIBUTIONS</b>			
Cadasil programs	-	1,250	1,250
ALD/AMN programs	-	14,375	14,375
CTX research programs	-	250	250
Globoid Cell Krabbes program	-	4,200	4,200
Research Endowment	-	13,610	13,610
General Research	-	25	25
Program Services Endowment	-	668	668
Total research contributions	-	34,378	34,378
<b>MEMBERSHIPS</b>			
Family	17,535	-	17,535
Professional	2,490	-	2,490
Total memberships	20,025	-	20,025
<b>GRANTS</b>			
	-	-	-
<b>FUNDRAISING</b>			
Miscellaneous	2,540	-	2,540
Benefit drawing	12,100	-	12,100
Total fundraising	14,640	-	14,640
<b>INTEREST INCOME</b>			
	-	22,069	22,069
<b>TOTAL PUBLIC SUPPORT</b>	<b>\$ 371,328</b>	<b>\$ 56,447</b>	<b>\$ 427,775</b>

**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
Total general contributions	181,700	9,235	190,935
<b>CONFERENCES</b>			
National conference fees	10,615	-	10,615
Sponsorships and exhibitors	120,000	-	120,000
Auction	5,808	-	5,808
Total conferences	136,423	-	136,423
<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
Total research contributions	-	30,160	30,160
<b>MEMBERSHIPS</b>			
Family	16,410	-	16,410
Professional	1,680	-	1,680
Total memberships	18,090	-	18,090
<b>GRANTS</b>	10,000	-	10,000
<b>FUNDRAISING</b>			
Miscellaneous	2,088	-	2,088
Benefit drawing	10,745	-	10,745
Total fundraising	12,833	-	12,833
<b>INTEREST INCOME</b>	-	27,837	27,837
<b>TOTAL PUBLIC SUPPORT</b>	\$ 359,046	\$ 67,232	\$ 426,278