

**UNITED LEUKODYSTROPHY
FOUNDATION, INC.**

**FINANCIAL STATEMENTS
AS OF DECEMBER 31, 2020 AND 2019**

TOGETHER WITH AUDITOR'S REPORT



**Dugan &
Lopatka**

Certified Public Accountants

4320 WINFIELD ROAD, SUITE 450
WARRENVILLE, IL 60555
630 665 4440

duganlopatka.com

INDEPENDENT AUDITOR'S REPORT

To the Board of Governors of
United Leukodystrophy Foundation, Inc.

We have audited the accompanying financial statements of United Leukodystrophy Foundation, Inc. (a nonprofit organization), which comprise the statement of financial position as of December 31, 2020 and the related statements of activities, cash flows, and statements of functional expenses 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 audit 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 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 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.

Independent Auditor's Report
To the Board of Governors of
United Leukodystrophy Foundation, Inc.
Page two

Opinion

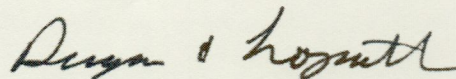
In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of United Leukodystrophy Foundation, Inc. as of December 31, 2020, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Report on 2019 Financial Statements

The financial statements of United Leukodystrophy Foundation, Inc. as of December 31, 2019, were audited by other accountants whose report dated April 23, 2020, expressed an unmodified opinion on those statements.

Report on Supplementary Information

Our audit was conducted for the purpose of forming an opinion on the basic financial statements taken as a whole. The accompanying 2020 supplementary information is presented for purposes of additional analysis and is not a required part of the basic 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. The 2019 supplementary information was subjected to the auditing procedures applied in the 2019 audit of the basic financial statements by other auditors, whose report on such information stated that it was fairly stated in all material respects in relation to the 2019 financial statements as a whole.



DUGAN & LOPATKA

Warrenville, Illinois
March 16, 2021

UNITED LEUKODYSTROPHY FOUNDATION, INC.
STATEMENT OF FINANCIAL POSITION
DECEMBER 31, 2020 AND 2019

<u>ASSETS</u>	<u>2020</u>	<u>2019</u>
CURRENT ASSETS:		
Cash and cash equivalents	\$ 439,980	\$ 102,499
Accounts receivable,	750	-
Prepaid expenses	7,221	2,748
Total current assets	447,951	105,247
OTHER ASSETS:		
Investments	931,328	833,526
PROPERTY AND EQUIPMENT:		
Office equipment	21,003	21,003
(Less) - accumulated depreciation	(20,873)	(20,684)
Net property and equipment	130	319
Total assets	\$ 1,379,409	\$ 939,092
<u>LIABILITIES AND NET ASSETS</u>		
CURRENT LIABILITIES:		
Accounts payable	\$ 2,251	\$ 7,138
Accrued expenses	1,804	1,791
Total current liabilities	4,055	8,929
NET ASSETS:		
Without donor restrictions	583,070	207,165
With donor restrictions	792,284	722,998
Total net assets	1,375,354	930,163
Total liabilities and net assets	\$ 1,379,409	\$ 939,092

The accompanying notes are an integral part of this statement.

UNITED LEUKODYSTROPHY FOUNDATION, INC.
STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2020

	2020		
	Without Donor Restrictions	With Donor Restrictions	Total
REVENUE AND PUBLIC SUPPORT:			
Contributions	\$ 464,979	\$ -	\$ 464,979
Conference fees	142,652	-	142,652
Research contributions	-	41,975	41,975
Membership fees	886	-	886
Fundraising, net direct benefit to donor	9,273	-	9,273
Interest income, net	5,571	13,815	19,386
Other income, debt forgiveness	10,300	-	10,300
	<u>633,661</u>	<u>55,790</u>	<u>689,451</u>
Total public support			
Net assets released from restrictions	41,863	(41,863)	-
	<u>675,524</u>	<u>13,927</u>	<u>689,451</u>
Total revenue			
FUNCTIONAL EXPENSES:			
Program and services	235,019	-	235,019
Management and general	70,138	-	70,138
Fundraising	16,521	-	16,521
	<u>321,678</u>	<u>-</u>	<u>321,678</u>
Total functional expenses			
Change in net assets before investment activity	353,846	13,927	367,773
Net appreciation on investments	22,059	55,359	77,418
	<u>375,905</u>	<u>69,286</u>	<u>445,191</u>
CHANGE IN NET ASSETS			
NET ASSETS, Beginning of year	207,165	722,998	930,163
	<u>207,165</u>	<u>722,998</u>	<u>930,163</u>
NET ASSETS, End of year	<u>\$ 583,070</u>	<u>\$ 792,284</u>	<u>\$ 1,375,354</u>

The accompanying notes are an integral part of this statement.

UNITED LEUKODYSTROPHY FOUNDATION, INC.
STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2019

	2019		
	Without Donor Restriction	With Donor Restriction	Total
REVENUE AND PUBLIC SUPPORT:			
Contributions	\$ 147,659	\$ -	\$ 147,659
Conference fees	189,004	-	189,004
Research contributions	-	34,378	34,378
Membership fees	20,025	-	20,025
Fundraising, net direct benefit to donor	14,640	-	14,640
Interest income, net	6,087	15,982	22,069
	<u>377,415</u>	<u>50,360</u>	<u>427,775</u>
Net assets released from restrictions	111,049	(111,049)	-
	<u>488,464</u>	<u>(60,689)</u>	<u>427,775</u>
FUNCTIONAL EXPENSES:			
Program and services	345,165	-	345,165
Management and general	64,883	-	64,883
Fundraising	24,265	-	24,265
	<u>434,313</u>	<u>-</u>	<u>434,313</u>
Change in net assets before investment activity	54,151	(60,689)	(6,538)
Net appreciation on investments	25,445	69,042	94,487
CHANGE IN NET ASSETS	79,596	8,353	87,949
NET ASSETS, Beginning of year	127,569	714,645	842,214
NET ASSETS, End of year	<u>\$ 207,165</u>	<u>\$ 722,998</u>	<u>\$ 930,163</u>

The accompanying notes are an integral part of this statement.

UNITED LEUKODYSTROPHY FOUNDATION, INC.
STATEMENT OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019

	<u>2020</u>	<u>2019</u>
CASH FLOWS FROM OPERATING ACTIVITIES:		
Change in net assets	\$ 445,191	\$ 87,949
Adjustments to reconcile change in net assets provided by operating activities:		
Depreciation	189	1,676
Net (appreciation) on investments	(77,418)	(94,487)
Changes in assets and liabilities -		
(Increase) decrease in accounts receivable	(750)	2,111
(Increase) decrease in prepaid expenses	(4,473)	3,206
Increase (decrease) in accounts payable	(4,887)	6,469
Increase in accrued expenses	13	591
	<u>357,865</u>	<u>7,515</u>
CASH FLOWS FROM INVESTING ACTIVITIES:		
Purchase of investments	(331,616)	(242,380)
Proceeds from sale of investments	311,232	274,933
	<u>(20,384)</u>	<u>32,553</u>
CASH FLOWS FROM FINANCING ACTIVITIES:		
Principal payment on capital lease	-	(1,430)
	<u>-</u>	<u>(1,430)</u>
NET INCREASE IN CASH	337,481	38,638
CASH AND CASH EQUIVALENTS, Beginning of year	<u>102,499</u>	<u>63,861</u>
CASH AND CASH EQUIVALENTS, End of year	<u>\$ 439,980</u>	<u>\$ 102,499</u>

The accompanying notes are an integral part of this statement.

UNITED LEUKODYSTROPHY FOUNDATION, INC.
STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2020

	Program Services		Program Total	Management and General	Fundraising	Direct Benefit to Donor	Total
	Education	Research					
SALARIES AND RELATED EXPENSES							
Salaries and wages	\$ 75,280	\$ -	\$ 75,280	\$ 1,619	\$ 4,047	\$ -	\$ 80,946
Payroll taxes	6,115	-	6,115	131	329	-	6,575
Workers compensation	490	-	490	-	-	-	490
Total salaries and related expenses	81,885	-	81,885	1,750	4,376	-	88,011
PROGRAM EXPENSE							
Bank fees	-	-	-	3,509	-	-	3,509
Depreciation	170	-	170	10	9	-	189
Dues and subscription, and filing fees	4,693	-	4,693	-	4,693	-	9,386
Gifts	-	-	-	139	-	-	139
Insurance	-	-	-	6,888	-	-	6,888
Miscellaneous	-	-	-	25	-	-	25
Postage	2,622	-	2,622	2,325	-	-	4,947
Printing and educational materials	2,525	-	2,525	6,183	-	-	8,708
Professional fees	2,662	-	2,662	45,255	5,324	-	53,241
Promotion and advertising	-	-	-	665	-	-	665
Supplies	2,876	-	2,876	339	169	-	3,384
Telephone	2,735	-	2,735	210	60	-	3,005
Total program expenses	18,283	-	18,283	65,548	10,255	-	94,086
TECHNOLOGY	16,918	-	16,918	940	940	-	18,798
SPECIAL PROJECTS							
Benefit drawing and prizes	-	-	-	-	-	8,986	8,986
Newsletter	4,572	-	4,572	-	-	-	4,572
Reserch grant	-	66,000	66,000	-	-	-	66,000
Total special projects	4,572	66,000	70,572	-	-	8,986	79,558
OCCUPANCY							
Rent	10,064	-	10,064	1,772	886	-	12,722
Utilities	1,092	-	1,092	128	64	-	1,284
Total occupancy	11,156	-	11,156	1,900	950	-	14,006
TRAVEL AND MEETING EXPENSES							
Travel	1,009	-	1,009	-	-	-	1,009
Meals and entertainment	1,413	-	1,413	-	-	-	1,413
Other conference and meeting	33,783	-	33,783	-	-	-	33,783
Total travel and meeting expenses	36,205	-	36,205	-	-	-	36,205
TOTAL FUNCTIONAL EXPENSES	\$ 169,019	\$ 66,000	\$ 235,019	\$ 70,138	\$ 16,521	\$ 8,986	\$ 330,664

The accompanying notes are an integral part of this statement.

UNITED LEUKODYSTROPHY FOUNDATION, INC.
STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2019

	Program Services		Program Total	Management and General	Fundraising	Direct Benefit to Donor	Total
	Education	Research					
SALARIES AND RELATED EXPENSES							
Salaries and wages	\$ 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
PROGRAM EXPENSE							
Bank fees	-	-	-	3,139	-	-	3,139
Depreciation	1,508	-	1,508	84	84	-	1,676
Dues, subscription, 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
TECHNOLOGY	19,777	-	19,777	1,099	1,099	-	21,975
SPECIAL PROJECTS							
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
OCCUPANCY							
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
TRAVEL AND MEETING EXPENSES							
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
TOTAL FUNCTIONAL EXPENSES	\$ 255,494	\$ 89,671	\$ 345,165	\$ 64,883	\$ 24,265	\$ 12,500	\$ 446,813

UNITED LEUKODYSTROPHY FOUNDATION, INC.
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2020 AND 2019

(1) NATURE OF BUSINESS AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES:

Nature of Business -

United Leukodystrophy Foundation, Inc. (the Organization), is an Indiana not-for-profit organization founded on June 15, 1982. The Organization provides voluntary health services to the patients and their families with information about their disease and assistance in identifying sources of medical care, social services, and genetic counseling.

The Organization works to establish a communication network among families, as well as increase public awareness and act as an information source for health care providers by promoting and supporting research into causes, treatment, and prevention of leukodystrophies.

The financial statements were available to be issued on March 16, 2021, with subsequent events being evaluated through this date.

The following summarizes the significant account policies and practices reflected in the accompanying financial statements.

Basis of Accounting -

The accounting records of the Organization are maintained on the accrual basis of accounting which recognizes revenue when earned and expenses as they are incurred.

Basis of Presentation -

The financial statements of the Organization have been prepared in accordance with U.S. generally accepted accounting principles (GAAP). Under GAAP, the Organization is required to report information regarding its financial position and activities according to two classes of net assets which are: without donor restrictions and with donor restrictions.

Without donor restrictions - Net assets that are not subject to donor-imposed stipulations and may be expensed for any purpose in performing the primary objectives of the Foundation. These net assets may be used at the discretion of management and the board of directors.

With donor restrictions - Net assets subject to donor-imposed stipulations. Some donor restrictions are temporary in nature; those restrictions will be met either by actions of the Foundation and/or the passage of time. Other donor restrictions are perpetual in nature, where the donor has stipulated the funds be maintained in perpetuity.

Cash and Cash Equivalents -

For purposes of the statement of 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 know amounts of cash. The Organization considers all highly liquid investments purchased with a maturity of three months or less to be cash equivalents.

(1) NATURE OF BUSINESS AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES:

(Continued)

Accounts Receivable -

Receivables are reported at the amount management expects to collect on balances outstanding at year end. Management provides for probable uncollectible amounts through a provision for bad debt expense and an adjustment to a valuation allowance based on its assessment of the current status of the individual accounts. Balances that are still outstanding after management has used reasonable collection efforts are written off through a charge to the valuation allowance and a credit to accounts receivable. Changes in the valuation allowance have not been material to the financial statements.

Investments -

The Organization carries investments in marketable securities (including corporate bonds and notes, corporate stock, and mutual funds), with readily determinable fair values at their fair values in the statement of financial position. Money market funds included in the investment portfolio are reported at cost, which approximates fair value, and are included as investments in the statement of financial position. Unrealized gains and losses are included in revenue in the accompanying statement of activities. Investment income is reported net of external investment expenses.

Property and Equipment -

Property and equipment are stated at cost or fair value if contributed. The Organization capitalizes all acquisitions of property and equipment, in excess of \$1,000 or more, and a useful life when acquired for more than one year. Depreciation is provided on the straight-line method over the estimated useful lives of the assets. Depreciation expense is \$189 and \$1,676 for the years ended December 31, 2020 and 2019, respectively.

Revenue Recognition for Contributions -

The Organization recognizes contributions when cash, securities, or other assets, an unconditional promise to give, or a notification of a beneficial interest are received. Conditional promises to give; that is, those with a measurable performance or other barrier and a right of return, are not recognized until the conditions on which they depend have been met.

The Organization reports gifts of cash and other assets as restricted support if they are received with donor stipulations that limit the use of the assets, or if they are designated as support for future periods. 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 to net assets without donor restrictions and reported in the statement of activities as net assets released from restrictions. Donor-restricted contributions, whose restrictions are met in the same period as received, are shown as contributions without donor restrictions on the statement of activities.

(1) NATURE OF BUSINESS AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES:
(Continued)

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 Organization. Revenues from conferences are recognized at the time of the associated event.

Membership Fees -

The Organization provided an annual membership to families, which provided them a discount for the annual conference registration fee and a quarterly newsletter. Memberships were discontinued in 2019.

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 received donated services from a variety of unpaid volunteers assisting the Organization in its charitable purpose. No amount has been recognized for these services in the statement of activities because the criteria for recognition has 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 \$-0- and \$3,384 for the years ended December 31, 2020 and 2019, respectively. These amounts are included in contribution revenue and allocated between the functional expense categories on the statement of activities.

Income Taxes -

The Organization qualifies for exemption 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.

Use of Estimates -

The preparation of financial statements in conformity with generally accepted accounting principles 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.

Functional Allocation of Expenses -

The financial statements report certain categories of expenses that are attributed to more than one program or supporting function. Therefore, expenses require allocation on a reasonable basis that is consistently applied. The expenses that are allocated include salaries and wages, payroll taxes, marketing, occupancy, meetings and seminars, and other expenses which are allocated on the basis of estimates of time and effort.

(2) FAIR VALUE MEASUREMENTS:

The Organization's investments are reported at fair value in the statements of financial position. The methods used to measure fair value may produce an amount that may not be indicative of net realizable value or reflective of future fair values.

Furthermore, although The Organization believes its valuation methods are appropriate and consistent with methods used by other market participants, the use of different methodologies or assumptions to determine the fair value of certain financial instruments could result in a different fair value measurement at the reporting date.

The fair value measurement accounting literature establishes a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. This hierarchy consists of three broad levels:

Level 1: Inputs consist of unadjusted quoted prices in active markets for identical assets and have the highest priority.

Level 2: Inputs consist primarily of quoted prices for similar assets.

Level 3: Inputs are unobservable and have the lowest priority. The Organization uses appropriate valuation techniques based on the available inputs to measure the fair value of its investments.

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

Mutual Funds - Valued at the daily closing price as reported by the fund. Mutual funds held by The Organization are open-ended mutual funds that are registered with the Securities and Exchange Commission. These funds are required to publish their daily net asset value and to transact at that price. The mutual funds held by The Organization are deemed to be actively traded.

On December 31, 2020 and 2019, investments are stated at fair value and consist primarily of mutual funds as follows:

	2020			
	Level 1	Level 2	Level 3	Total
Mutual Funds				
Fixed income	\$ 352,741	\$ -	\$ -	\$ 352,741
Equities	456,571	-	-	456,571
Alternative	<u>87,319</u>	<u>-</u>	<u>-</u>	<u>87,319</u>
Total assets at fair value	<u>\$ 896,631</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 896,631</u>
Cash equivalents at cost				<u>34,697</u>
Total investments				<u>\$ 931,328</u>

(2) FAIR VALUE MEASUREMENTS:

	2019			
	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Mutual Funds				
Fixed income	\$ 396,082	\$ -	\$ -	\$ 396,082
Equities	344,634	-	-	344,634
Alternative	<u>71,969</u>	<u>-</u>	<u>-</u>	<u>71,969</u>
Total assets at fair value	<u>\$ 812,685</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 812,685</u>
Cash equivalents at cost				<u>20,841</u>
Total investments				<u>\$ 833,526</u>

(3) NET ASSETS WITH DONOR RESTRICTIONS:

Net assets with donor restrictions are restricted for the following purpose on December 31, 2020 and 2019:

	<u>2020</u>	<u>2019</u>
Program endowment	\$ 129,517	\$ 129,654
Research and grants endowment	<u>662,767</u>	<u>593,344</u>
Total net assets with donor restrictions	<u>\$ 792,284</u>	<u>\$ 722,998</u>

(4) LEASE COMMITMENT:

The Organization leases its office space under an operating lease, with monthly rent of \$667 that expires July 8, 2021. The Organization also rents event space for conferences under short-term rental agreements. Rent expense is \$12,772 and \$47,725, for the years ended December 31, 2020 and 2019, respectively. Future minimum lease payment are as follows:

2021	\$ 4,002
------	----------

(5) PAYCHECK PROTECTION PROGRAM

The Organization received a loan from the Small Business Administration (SBA) in the amount of \$10,300 under the Paycheck Protection Program established by the Coronavirus Aid, Relief, and Economic Security (CARES) Act. The loan was subject to a note dated April 2020. The Organization applied for, and has been notified that, \$10,300 in eligible expenditures for payroll and other expenses described in the CARES Act has been approved and the loan was forgiven by the SBA on December 23, 2020. Loan forgiveness is reflected in the other income in the accompanying statement of activities.

(6) ENDOWMENT:

The Organization's endowment consists of two endowment funds established to support education and research programs. The endowment includes both donor-restricted endowment fund and funds designated by the Board of Directors to function as endowments (board-designated endowment funds). As required by U.S. GAAP, 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 the preservation of the fair value of the original gift as of the gift date of the donor-restricted endowment funds unless there are 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 the donor-restricted endowment fund is classified as with donor-restricted net assets for time or the purpose, 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) the duration and preservation of the various funds, (2) the purposes of the donor-restricted endowment funds, (3) general economic conditions, (4) the possible effect of inflation and deflation, (5) the expected total return from income and the appreciation of investments, (6) other resources of the Foundation, and (7) the Foundation's investment policies.

The composition of net assets by type of endowment funds on December 31, 2020 and 2019, is as follows:

	2020		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Board-designated endowment funds	\$ 139,044	\$ -	\$ 139,044
Donor-restricted endowment funds:			
Donor-restricted gifts	-	292,284	292,284
Original donor-restricted gift amount and amounts required to be maintained in perpetuity by donor	<u>-</u>	<u>500,000</u>	<u>500,000</u>
	<u>\$ 139,044</u>	<u>\$ 792,284</u>	<u>\$ 931,328</u>
	2019		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Board-designated endowment funds	\$ 110,528	\$ -	\$ 110,528
Donor-restricted endowment funds:			
Donor-restricted gifts	-	222,998	222,998
Original donor-restricted gift amount and amounts required to be maintained in perpetuity by donor	<u>-</u>	<u>500,000</u>	<u>500,000</u>
	<u>\$ 110,528</u>	<u>\$ 722,998</u>	<u>\$ 833,526</u>

(6) ENDOWMENT: (Continued)

From time to time, certain donor-restricted endowment funds may have fair values less than the amount required to be maintained by donors or by law (underwater endowments). The Organization has interpreted UPMIFA to permit spending from underwater endowments in accordance with prudent measures required under law. There were no underwater endowments as of December 31, 2020 and 2019.

Changes in endowment net assets for the years ended December 31, 2020 and 2019, are as follows:

	2020		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Endowment net assets, beginning of year	\$ 110,528	\$ 722,998	\$ 833,526
Investment return			
Net interest and dividend income	5,571	13,815	19,386
Net depreciation, realized and unrealized	22,059	55,359	77,418
Contributions	-	41,975	41,975
Board designation to move			
Contribution to endowment	886	-	886
Appropriation of endowment assets for expenditure	<u>-</u>	<u>(41,863)</u>	<u>(41,863)</u>
Endowment net assets, end of year	<u>\$ 139,044</u>	<u>\$ 792,284</u>	<u>\$ 931,328</u>
	2019		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
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 depreciation, realized and unrealized	25,445	69,042	94,487
Contributions	-	34,378	34,378
Board designation to move			
Contribution to endowment	22,050	-	22,050
Appropriation of endowment assets for expenditure	<u>-</u>	<u>(111,049)</u>	<u>(111,049)</u>
Endowment net assets, end of year	<u>\$ 110,528</u>	<u>\$ 722,998</u>	<u>\$ 833,526</u>

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.

(6) ENDOWMENT: (Continued)

Endowment assets include those assets of the 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 objective, 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 objective 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 the endowment assets held in perpetuity, or for a specified term, as well as to provide additional real growth through new gifts and investment return.

(7) LIQUIDITY AND AVAILABILITY:

	<u>2020</u>	<u>2019</u>
Financial assets -		
Cash and cash equivalents	\$ 439,980	\$ 102,499
Investments	931,328	833,526
Accounts receivable	<u>750</u>	<u>-</u>
Total financial assets	1,372,058	936,025
Less amounts not available to be used within one year:		
Net assets with donor restriction	(792,284)	(722,998)
Net assets with board designations	<u>(139,044)</u>	<u>(110,528)</u>
	(931,328)	(833,526)
Financial assets available to meet cash needs for general expenditures; that is, without donor or other restrictions limiting their use within one year	<u>\$ 440,730</u>	<u>\$ 102,499</u>

The Organization manages its liquidity and reserves the following three guiding principles:

- operating within a prudent range of financial soundness and stability.
- maintaining adequate liquid assets to fund near-term operating needs.
- maintaining sufficient reserves to provide reasonable assurance that long-term obligations will be discharged.

(8) CONCENTRATION OF CONTRIBUTION REVENUE:

For the year ended December 31, 2020, approximately 49% of total contributions came from one donor as a bequest.

(9) MANAGEMENT RESPONSE TO COVID-19 PANDEMIC:

In March 2020, the World Health Organization declared the novel strain of coronavirus (COVID-19) a global pandemic and recommended containment and mitigation measures worldwide. As a part of these mitigation measures, the organization had to cancel fundraising events and conference or hold them as virtual events, which resulted in decreased public support and the Organization's ability to assist families. In response to the effects of COVID-19, the Organization's board members are implementing strategies to help mitigate the losses in relation to this pandemic. The Organization cannot reasonably estimate the length or severity of this pandemic, or the extent to which the disruption from this pandemic may impact operations and financial statements.

UNITED LEUKODYSTROPHY FOUNDATION, INC.
SCHEDULE OF PUBLIC SUPPORT
FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019

	2020			2019		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
GENERAL CONTRIBUTIONS						
Contributions	\$ 215,925	\$ -	\$ 215,925	\$ 98,488	\$ -	\$ 98,488
Memorials	241,106	-	241,106	35,207	-	35,207
Outside fundraiser	7,948	-	7,948	13,964	-	13,964
Total general contribution	464,979	-	464,979	147,659	-	147,659
CONFERENCES						
National conference fees	-	-	-	9,125	-	9,125
Sponsorships and exhibitors	142,652	-	142,652	174,927	-	174,927
Auction	-	-	-	4,952	-	4,952
Total conferences	142,652	-	142,652	189,004	-	189,004
RESEARCH CONTRIBUTIONS						
Cadasil programs	-	-	-	-	1,250	1,250
ALD/AMN programs	-	8,200	8,200	-	14,375	14,375
MLD programs	-	3,623	3,623	-	250	250
CTX research programs	-	540	540	-	-	-
Globoid cell krabbes program	-	900	900	-	4,200	4,200
Research endowment	-	27,573	27,573	-	13,610	13,610
General research	-	-	-	-	25	25
Program services endowment	-	1,139	1,139	-	668	668
Total research contributions	-	41,975	41,975	-	34,378	34,378
MEMERHIPS						
Family	660	-	660	17,535	-	17,535
Professional	100	-	100	2,490	-	2,490
Newsletter subscription	126	-	126	-	-	-
Total memberships	886	-	886	20,025	-	20,025
FUNDRAISING						
Miscellaneous	7,109	-	7,109	2,540	-	2,540
Benefit drawing	2,164	-	2,164	12,100	-	12,100
Total fundraising	9,273	-	9,273	14,640	-	14,640
INTEREST INCOME						
	-	19,386	19,386	-	22,069	22,069
OTHER INCOME, debt forgiveness						
	10,300	-	10,300	-	-	-
TOTAL PUBLIC SUPPORT	\$ 617,790	\$ 61,361	\$ 689,451	\$ 371,328	\$ 56,447	\$ 427,775