

**UNITED LEUKODYSTROPHY  
FOUNDATION, INC.**

**FINANCIAL STATEMENTS  
AS OF DECEMBER 31, 2022 AND 2021**

**TOGETHER WITH AUDITOR'S REPORT**

## INDEPENDENT AUDITOR'S REPORT

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

### *Opinion*

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, 2022 and 2021, and the related statements of activities, cash flows, and functional expenses for the years then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of United Leukodystrophy Foundation, Inc. as of December 31, 2022 and 2021, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

### *Responsibilities of Management for the Financial Statements*

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

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, which raise substantial doubt about United Leukodystrophy Foundation's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

### *Auditor's Responsibility for the Audit of the Financial Statements*

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements, including omissions, are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

***Auditor's Responsibility for the Audit of the Financial Statements-(Continued)***

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of United Leukodystrophy Foundation's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events considered in the aggregate, which raise substantial doubt about United Leukodystrophy Foundation's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

***Report on Supplementary Information***

Our audit was conducted for the purpose of forming an opinion on the financial statements as a whole. The accompanying schedule of public support 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.



DUGAN & LOPATKA

UNITED LEUKODYSTROPHY FOUNDATION, INC.  
STATEMENT OF FINANCIAL POSITION  
DECEMBER 31, 2022 AND 2021

A S S E T S

	<u>2022</u>	<u>2021</u>
CURRENT ASSETS:		
Cash and cash equivalents	\$ 250,074	\$ 241,727
Prepaid expenses	<u>2,206</u>	<u>7,240</u>
Total current assets	<u>252,280</u>	<u>248,967</u>
OTHER ASSETS:		
Investments	1,199,928	1,392,526
Right of use assets	<u>4,178</u>	<u>-</u>
Total other assets	<u>1,204,106</u>	<u>1,392,526</u>
PROPERTY AND EQUIPMENT:		
Office equipment	21,003	21,003
(Less) - accumulated depreciation	<u>(21,003)</u>	<u>(21,003)</u>
Total assets	<u>\$ 1,456,386</u>	<u>\$ 1,641,493</u>

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES:		
Accounts payable	\$ 645	\$ 6,864
Accrued expenses	4,406	6,715
Deferred revenue	-	3,192
Operating lease liability	<u>4,294</u>	<u>-</u>
Total current liabilities	<u>9,345</u>	<u>16,771</u>
NET ASSETS:		
Without donor restrictions	649,318	719,537
With donor restrictions	<u>797,723</u>	<u>905,185</u>
Total net assets	<u>1,447,041</u>	<u>1,624,722</u>
Total liabilities and net assets	<u>\$ 1,456,386</u>	<u>\$ 1,641,493</u>

The accompanying notes are an integral part of this statement.

UNITED LEUKODYSTROPHY FOUNDATION, INC.  
STATEMENT OF ACTIVITIES  
FOR THE YEARS ENDED DECEMBER 31, 2022 AND 2021

	2022			2021		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restriction	With Donor Restriction	Total
REVENUE AND PUBLIC SUPPORT:						
Contributions	\$ 212,998	\$ -	\$ 212,998	\$ 290,773	\$ -	\$ 290,773
Conference fees	245,345	-	245,345	145,215	-	145,215
Endowment contributions	-	104,917	104,917	-	131,129	131,129
Subscription fees	4,486	-	4,486	3,625	-	3,625
Fundraising, net direct benefit to donor	5,186	-	5,186	1,649	-	1,649
Interest and dividend income, net	14,429	22,958	37,387	19,015	24,115	43,130
Net assets released from restrictions	102,683	(102,683)	-	84,011	(84,011)	-
 Total revenue	 585,127	 25,192	 610,319	 544,288	 71,233	 615,521
FUNCTIONAL EXPENSES:						
Program and services	358,264	-	358,264	284,697	-	284,697
Management and general	120,632	-	120,632	75,904	-	75,904
Fundraising	78,885	-	78,885	76,589	-	76,589
 Total functional expenses	 557,781	 -	 557,781	 437,190	 -	 437,190
Change in net assets before investment activity	27,346	25,192	52,538	107,098	71,233	178,331
Net appreciation (depreciation) on investments	(97,565)	(132,654)	(230,219)	29,369	41,668	71,037
CHANGE IN NET ASSETS	(70,219)	(107,462)	(177,681)	136,467	112,901	249,368
NET ASSETS, Beginning of year	719,537	905,185	1,624,722	583,070	792,284	1,375,354
NET ASSETS, End of year	\$ 649,318	\$ 797,723	\$ 1,447,041	\$ 719,537	\$ 905,185	\$ 1,624,722

The accompanying notes are an integral part of this statement.

UNITED LEUKODYSTROPHY FOUNDATION, INC.  
STATEMENT OF CASH FLOWS  
FOR THE YEARS ENDED DECEMBER 31, 2022 AND 2021

	<u>2022</u>	<u>2021</u>
CASH FLOWS FROM OPERATING ACTIVITIES:		
Change in net assets	\$ (177,681)	\$ 249,368
Adjustments to reconcile change in net assets (used in) provided by operating activities:		
Depreciation	-	130
Noncash portion of lease expense for operating lease	4,178	-
Repayment of lease liability - operating lease	(4,062)	-
Net realized and unrealized (gain) loss on investments	230,219	(71,037)
Changes in assets and liabilities -		
Decrease in accounts receivable	-	750
(Increase) decrease in prepaid expenses	5,034	(19)
Increase (decrease) in accounts payable	(6,219)	4,613
Increase (decrease) in accrued expenses	(2,309)	4,911
Increase (decrease) in deferred revenue	(3,192)	3,192
Net cash provided by operating activities	<u>45,968</u>	<u>191,908</u>
CASH FLOWS FROM INVESTING ACTIVITIES:		
Purchase of investments	(2,738,463)	(749,747)
Proceeds from sale of investments	<u>2,700,842</u>	<u>359,586</u>
Net cash (used in) investing activities	<u>(37,621)</u>	<u>(390,161)</u>
NET INCREASE IN CASH	8,347	(198,253)
CASH AND CASH EQUIVALENTS, Beginning of year	<u>241,727</u>	<u>439,980</u>
CASH AND CASH EQUIVALENTS, End of year	<u>\$ 250,074</u>	<u>\$ 241,727</u>
NON-CASH INVESTMENT AND FINANCING ACTIVITIES		
Right of use acquired through operating lease	<u>\$ 8,120</u>	<u>\$ -</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, 2022

	Program Services		Program Total	Management and General	Fundraising	Direct Benefit to Donor	Total
	Education	Research					
<b>SALARIES AND RELATED EXPENSES</b>							
Salaries and wages	\$ 17,200	\$ 17,200	\$ 34,400	\$ 85,998	\$ 51,597	\$ -	\$ 171,995
Payroll taxes	5,920	900	6,820	4,364	4,073	-	15,257
Workers compensation	584	89	673	430	402	-	1,505
Total salaries and related expenses	23,704	18,189	41,893	90,792	56,072	-	188,757
<b>PROGRAM EXPENSE</b>							
Bank fees	-	-	-	-	3,914	-	3,914
Dues and subscription, and filing fees	332	300	632	300	7,325	-	8,257
Insurance	1,367	208	1,575	1,008	941	-	3,524
Miscellaneous	-	-	-	2,000	-	-	2,000
Postage	343	4	347	21	2,254	-	2,622
Printing and educational materials	5,584	-	5,584	-	-	-	5,584
Professional fees	6,678	280	6,958	18,484	1,267	-	26,709
Promotion and advertising	3,811	-	3,811	-	-	-	3,811
Supplies	2,743	138	2,881	668	624	-	4,173
Total program expenses	20,858	930	21,788	22,481	16,325	-	60,594
<b>TECHNOLOGY</b>							
	42,395	630	43,025	3,056	2,853	-	48,934
<b>SPECIAL PROJECTS</b>							
Benefit drawing and prizes	-	-	-	-	-	9,515	9,515
Newsletter	2,454	-	2,454	-	-	-	2,454
Research grant	-	84,940	84,940	-	-	-	84,940
Total special projects	2,454	84,940	87,394	-	-	9,515	96,909
<b>OCCUPANCY</b>							
Rent	3,211	488	3,699	2,387	2,209	-	8,295
Utilities	2,072	315	2,387	1,525	1,426	-	5,338
Total occupancy	5,283	803	6,086	3,912	3,635	-	13,633
<b>TRAVEL AND MEETING EXPENSES</b>							
Travel	14,851	-	14,851	391	-	-	15,242
Other conference and meeting	143,227	-	143,227	-	-	-	143,227
Total travel and meeting expenses	158,078	-	158,078	391	-	-	158,469
<b>TOTAL FUNCTIONAL EXPENSES</b>	<b>\$ 252,772</b>	<b>\$ 105,492</b>	<b>\$ 358,264</b>	<b>\$ 120,632</b>	<b>\$ 78,885</b>	<b>\$ 9,515</b>	<b>\$ 567,296</b>

The accompanying notes are an integral part of this statement.

UNITED LEUKODYSTROPHY FOUNDATION, INC.  
STATEMENT OF FUNCTIONAL EXPENSES  
FOR THE YEAR ENDED DECEMBER 31, 2021

	Program Services		Program Total	Management and General	Fundraising	Direct Benefit to Donor	Total
	Education	Research					
<b>SALARIES AND RELATED EXPENSES</b>							
Salaries and wages	\$ 56,491	\$ 8,620	\$ 65,111	\$ 41,675	\$ 38,839	\$ -	\$ 145,625
Payroll taxes	5,137	781	5,918	3,787	3,535	-	13,240
Workers compensation	260	40	300	191	179	-	670
Total salaries and related expenses	61,888	9,441	71,329	45,653	42,553	-	159,535
<b>PROGRAM EXPENSE</b>							
Bank fees	-	-	-	194	2,076	-	2,270
Depreciation	-	-	-	130	-	-	130
Dues, subscription, and filing fees	332	300	632	300	7,843	-	8,775
Gifts	-	-	-	139	-	-	139
Insurance	1,833	279	2,112	1,351	1,261	-	4,724
Miscellaneous	167	25	192	124	115	-	431
Postage	4,360	169	4,529	817	10,236	-	15,582
Printing and educational materials	4,062	-	4,062	-	3,528	-	7,590
Professional fees	28,668	346	29,014	18,308	1,566	-	48,888
Promotion and advertising	352	-	352	-	100	-	452
Supplies	995	151	1,146	734	685	-	2,565
Telephone	880	134	1,014	648	606	-	2,268
Total program expenses	41,649	1,404	43,053	22,745	28,016	-	93,814
<b>TECHNOLOGY</b>							
	11,784	651	12,435	3,157	2,948	-	18,540
<b>SPECIAL PROJECTS</b>							
Benefit drawing and prizes	-	-	-	-	-	1,660	1,660
Newsletter	2,410	-	2,410	-	-	-	2,410
Research grant	-	68,000	68,000	-	-	-	68,000
Total special projects	2,410	68,000	70,410	-	-	1,660	72,070
<b>OCCUPANCY</b>							
Rent	3,890	591	4,481	3,280	2,677	-	10,438
Utilities	575	87	662	423	395	-	1,480
Total occupancy	4,465	678	5,143	3,703	3,072	-	11,918
<b>TRAVEL AND MEETING EXPENSES</b>							
Travel	-	-	-	435	-	-	435
Meals and entertainment	-	-	-	211	-	-	211
Other conference and meeting	82,327	-	82,327	-	-	-	82,327
Total travel and meeting expenses	82,327	-	82,327	646	-	-	82,973
<b>TOTAL FUNCTIONAL EXPENSES</b>	<b>\$ 204,523</b>	<b>\$ 80,174</b>	<b>\$ 284,697</b>	<b>\$ 75,904</b>	<b>\$ 76,589</b>	<b>\$ 1,660</b>	<b>\$ 438,850</b>

The accompanying notes are an integral part of this statement.



UNITED LEUKODYSTROPHY FOUNDATION, INC.  
NOTES TO FINANCIAL STATEMENTS  
DECEMBER 31, 2022 AND 2021

(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 May 12, 2023, 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 known 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. There are no receivables or valuation allowance as of December 31, 2022 and 2021.

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 \$-0- and \$130 for the years ended December 31, 2022 and 2021, respectively.

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.

Subscription Fees -

The Organization started offering subscriptions for a quarterly printed newsletter in 2021. The organization offers one year (print in mail) or free online subscriptions. Revenues from subscription fees are recognized at the time of publication of the newsletters. The Organization records deferred revenue when deposits for the newsletter's subscriptions are received and recognizes the revenue as the newsletters are published. Deferred revenue related to subscription revenues was \$-0, 3,192, and \$0- as of December 31, 2022, 2021 and 2020, respectively.

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

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.

Leases -

The Organization determines if an arrangement is a lease or contains a lease at inception of the contract. The Organization's operating lease are presented in operating lease right-of-use assets, current portion of operating lease liabilities, and long-term portion of operating lease liabilities in the accompanying balance sheet as of December 31, 2022.

Operating lease right-of-use assets and lease liabilities are measured based on the present value of future lease payments over the lease term at each lease's commencement date. As most of the Organization's lease do not specify their implicit rate, the Organization has elected a practical expedient to use the nominal yield, at lease inception, applicable to U.S. Treasury instruments with a maturity of similar length of the lease term.

Operating lease right-of-use assets include all fixed contractual lease payments and initial direct costs incurred by the Organization, less any lease incentives the Organization receives from the lessor. The Organization has elected a practical expedient to account for lease and non-lease components together as a single lease component. The terms of the Organization's lease generally contain lease payments and reimbursements to the lessor of the Organization's proportionate share of common area maintenance (CAM), real estate taxes and other pass-through charges. Only the fixed lease components are included in the right-of-use assets and lease liabilities. Additionally, the Organization has elected not to apply these lease accounting policies to lease with a term of one year or less at the commencement date.

Operating lease expense for lease payments is recognized on a straight-line basis over the terms of each lease. Variable lease components include CAM, real estate taxes and other charges and are recorded as lease expense as incurred.

The Organization's lease can contain options granting the right to renew or extend the term of the lease for specified option periods. The decision as to whether the Organization will exercise the renewal options is generally at the Organization's sole discretion. The Organization includes lease extensions in the lease term when it is reasonably certain that the Organization will exercise the extension.

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

Income Taxes -

The Organization has been determined by the Internal Revenue Services to be exempt from income tax under Section 501(c)(3) of the internal Revenue Code and it is exempt from federal income taxes, except for taxes on unrelated business income generated from unrelated trade or business activities. The Organization files informational returns in the U.S. federal jurisdiction. With few exceptions, the Organization is no longer subject to U.S. federal, state and local, or non-U.S. income tax examinations by tax authorities for fiscal year before 2019. The Organization does not expect a material net change in unrecognized tax benefits in the next twelve months.

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, occupancy, due and subscription, insurance and other expenses which are allocated on the basis of estimates of time and effort.

New Accounting Pronouncement -

Effective January 1, 2022, the Organization adopted ASU 2016-02, *Leases* (Topic 842) and subsequent amendments. Under ASU 2016-02, all of the Organization's real estate and equipment leases that have lease terms exceeding twelve months will now be required to be recognized on the balance sheet as amortizable right-of-use assets accompanied by liabilities for the present value of the lease payments that the Organization is obligated to make in order to obtain control of the leased assets for the duration of each lease term.

Lease expense, under these amendments, will be recognized in different patterns depending on whether the underlying lease is an operating lease or a finance lease. Lease expense for operating leases will be recognized as a single expense using the straight-line method over the term of the lease, which includes options to renew the lease that the Organization is reasonably expected to exercise. Finance lease expense will consist of two components, interest expense on the lease obligation payable and straight-line amortization of the right-of-use asset.

Implementation of these amendments is reflected using the modified retrospective method as of January 1, 2022. Upon implementation, the Organization elected an available package of practical expedients permitted under the transition guidance included in ASU 2018-11, *Leases* (Topic 842) – *Targeted Improvements* that permits the Organization to carry forward the historical lease identification, classification and initial direct costs associated with the Organization's pre-existing leases. The implementation of the amendments did not materially impact the Organization's net earnings or cash flows.

(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, 2022 and 2021, investments are stated at fair value and consist primarily of mutual funds as follows:

	<u>2022</u>			
	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Mutual Funds				
Fixed income	\$ 507,927	\$ -	\$ -	\$ 507,927
Equities	547,192	-	-	547,192
Alternative	<u>109,117</u>	<u>-</u>	<u>-</u>	<u>109,117</u>
Total assets at fair value	<u>\$ 1,164,236</u>	<u>\$ -</u>	<u>\$ -</u>	1,164,236
Cash equivalents at cost				<u>35,692</u>
Total investments				<u>\$ 1,199,928</u>

(2) FAIR VALUE MEASUREMENTS: (Continued)

	2021			
	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Mutual Funds				
Fixed income	\$ 496,331	\$ -	\$ -	\$ 496,331
Equities	627,535	-	-	627,535
Alternative	<u>153,256</u>	<u>-</u>	<u>-</u>	<u>153,256</u>
Total assets at fair value	<u>\$ 1,277,122</u>	<u>\$ -</u>	<u>\$ -</u>	1,227,122
Cash equivalents at cost				<u>115,404</u>
Total investments				<u>\$ 1,392,526</u>

(3) NET ASSETS WITH DONOR RESTRICTIONS:

Net assets with donor restrictions are restricted for the following purpose on December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Program endowment	\$ 131,678	\$ 131,109
Research and grants endowment	609,372	721,158
Family Assistance endowment	<u>56,673</u>	<u>52,918</u>
Total net assets with donor restrictions	<u>\$ 797,723</u>	<u>\$ 905,185</u>

(4) CONCENTRATION OF CONTRIBUTION REVENUE:

For the year ended December 31, 2022, approximately 10% of total contributions came from one donor as a bequest.

(5) LEASES:

The Organization lease its facility under operating lease with non-related party. The Organization is also responsible for its share of insurance, and maintenance costs for the buildings. The operating lease will expire in 2023.

The components of lease expense for the year ending December 31, 2022 are as follows:

Operating lease cost	\$ 8,120
Variable lease cost	<u>175</u>
Total lease expense	<u>\$ 8,295</u>

(5) LEASES: (Continued)

Future minimum lease payment under noncancelable lease as of December 31, 2022 are as follows:

2023	\$ <u>4,350</u>
Total future minimum lease payments	4,350
Less imputed interest included	<u>(56)</u>
Present value of net minimum lease payments	<u>\$ 4,294</u>

The following provides additional information related to the Organization's lease as of and for the year ended December 31, 2022:

Current portion of lease liabilities	\$ 4,294
Long-term portion of lease liabilities	<u>-</u>
Total lease liabilities	<u>\$ 4,294</u>
Weighted average lease term	1 year
Weighted average discount rate	2.88%

Cash paid for amounts included in the measurements of the Organization's lease for the year ended December 31, 2022 is as follows:

Operating cash from operating leases	\$ 8,120
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(6) ENDOWMENT:

The Organization's endowment consists of three endowment funds established to support programs, family assistance 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.

(6) 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) 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, 2022 and 2021, is as follows:

	<u>2022</u>		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Board-designated endowment funds	\$ 402,205	\$ -	\$ 402,205
Donor-restricted endowment funds:			
Donor-restricted gifts	-	297,723	297,723
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>\$ 402,205</u>	<u>\$ 797,723</u>	<u>\$ 1,199,928</u>
	<u>2021</u>		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Board-designated endowment funds	\$ 487,341	\$ -	\$ 487,341
Donor-restricted endowment funds:			
Donor-restricted gifts	-	405,185	405,185
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>\$ 487,341</u>	<u>\$ 905,185</u>	<u>\$ 1,392,526</u>

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, 2022 and 2021.



(6) ENDOWMENT: (Continued)

Changes in endowment net assets for the years ended December 31, 2022 and 2021, are as follows:

	<u>2022</u>		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Endowment net assets, beginning of year	\$ 487,341	\$ 905,185	\$ 1,392,526
Investment return			
Net interest and dividend income	14,429	22,958	37,387
Net realized and unrealized (loss)	(97,565)	(132,654)	(230,219)
Contributions	-	104,917	104,917
Appropriation of endowment assets for expenditure	<u>(2,000)</u>	<u>(102,683)</u>	<u>(104,683)</u>
Endowment net assets, end of year	<u>\$ 402,205</u>	<u>\$ 797,723</u>	<u>\$ 1,199,928</u>

	<u>2021</u>		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Endowment net assets, beginning of year	\$ 139,044	\$ 792,284	\$ 931,328
Investment return			
Net interest and dividend income	19,015	24,115	43,130
Net realized and unrealized gain	29,369	41,668	71,037
Contributions	-	131,129	131,129
Board designation to move contribution to endowment	299,913	-	299,913
Appropriation of endowment assets for expenditure	<u>-</u>	<u>(84,011)</u>	<u>(84,011)</u>
Endowment net assets, end of year	<u>\$ 487,341</u>	<u>\$ 905,185</u>	<u>\$ 1,392,526</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.

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.

(6) ENDOWMENT: (Continued)

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 twelve months 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>2022</u>	<u>2021</u>
Financial assets -		
Cash and cash equivalents	\$ 250,074	\$ 241,727
Investments	<u>1,199,928</u>	<u>1,392,526</u>
Total financial assets	<u>1,450,002</u>	<u>1,634,253</u>
Less amounts not available to be used within one year:		
Net assets with donor restriction	(797,723)	(905,185)
Net assets with board designations	<u>(402,205)</u>	<u>(487,341)</u>
	(1,199,928)	(1,392,526)
Financial assets available to meet cash needs for general expenditures: that is, without donor or other restrictions limiting their use within one year	<u>\$ 250,074</u>	<u>\$ 241,727</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.

UNITED LEUKODYSTROPHY FOUNDATION, INC.  
SCHEDULE OF PUBLIC SUPPORT  
FOR THE YEARS ENDED DECEMBER 31, 2022 AND 2021

	2022			2021		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
<b>GENERAL CONTRIBUTIONS</b>						
Contributions	\$ 212,998	\$ -	\$ 212,998	\$ 258,525	\$ -	\$ 258,525
Memorials	-	-	-	26,774	-	26,774
Outside fundraiser	-	-	-	5,474	-	5,474
Total general contribution	212,998	-	212,998	290,773	-	290,773
<b>CONFERENCES</b>						
National conference fees	16,887	-	16,887	2,280	-	2,280
Sponsorships and exhibitors	221,498	-	221,498	142,935	-	142,935
Auction	6,960	-	6,960	-	-	-
Total conferences	245,345	-	245,345	145,215	-	145,215
<b>ENDOWMENT CONTRIBUTIONS</b>						
ALD/AMN programs	-	16,800	16,800	-	31,350	31,350
MLD programs	-	-	-	-	200	200
CTX research programs	-	1,260	1,260	-	156	156
Globoid cell krabbes program	-	5,900	5,900	-	3,800	3,800
Research endowment	-	42,834	42,834	-	40,495	40,495
General research	-	33,800	33,800	-	38,050	38,050
Family Assistance endowment	-	3,754	3,754	-	15,486	15,486
Program services endowment	-	569	569	-	1,592	1,592
Total research contributions	-	104,917	104,917	-	131,129	131,129
<b>MEMBERSHIPS</b>						
Newsletter subscription	4,486	-	4,486	3,625	-	3,625
Total memberships	4,486	-	4,486	3,625	-	3,625
<b>FUNDRAISING</b>						
Miscellaneous	14,701	-	14,701	3,309	-	3,309
Benefit drawing	(9,515)	-	(9,515)	(1,660)	-	(1,660)
Total fundraising	5,186	-	5,186	1,649	-	1,649
<b>INTEREST AND DIVIDEND INCOME</b>						
	14,429	22,958	37,387	19,015	24,115	43,130
<b>TOTAL PUBLIC SUPPORT</b>	<b>\$ 482,444</b>	<b>\$ 127,875</b>	<b>\$ 610,319</b>	<b>\$ 460,277</b>	<b>\$ 155,244</b>	<b>\$ 615,521</b>