## UNITED LEUKODYSTROPHY FOUNDATION, INC.

FINANCIAL STATEMENTS
AS OF DECEMBER 31, 2024 and 2023

TOGETHER WITH AUDITOR'S REPORT

#### Certified Public Accountants

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#### 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, 2024 and 2023, 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, 2024 and 2023, 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.

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#### 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

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Warrenville, Illinois April 28, 2025

# UNITED LEUKODYSTROPHY FOUNDATION, INC. STATEMENT OF FINANCIAL POSITION DECEMBER 31, 2024 AND 2023

#### $\underline{ASSETS}$

	2024	2023
CURRENT ASSETS: Cash and cash equivalents Prepaid expenses	\$ 164,550 31,830	\$ 158,398 1,706
Total current assets	196,380	160,104
OTHER ASSETS: Investments Right of use assets	1,380,243	1,361,136 4,244
Total other assets	1,380,243	1,365,380
PROPERTY AND EQUIPMENT: Office equipment (Less) - accumulated depreciation  Net property and equipment	21,003 (21,003)	21,003 (21,003)
Total assets	\$ 1,576,623	\$ 1,525,484
<u>LIABILITIE</u>	S AND NET ASSETS	
CURRENT LIABILITIES: Accounts payable Accrued expenses Operating lease liability	\$ 880 - -	\$ 1,003 9,123 4,244
Total current liabilities	880	14,370
NET ASSETS: Without donor restrictions With donor restrictions	999,175 576,568	619,484 891,630
Total net assets	1,575,743	1,511,114

The accompanying notes are an integral part of this statement.

# UNITED LEUKODYSTROPHY FOUNDATION, INC. STATEMENT OF ACTIVITIES FOR THE YEARS ENDED DECEMBER 31, 2024 AND 2023

		2024				2023					
	Wit	hout Donor	With Donor	_	Without Donor		With Donor	_			
		estrictions	Restrictions	Total	Re	estriction	Restriction	Total			
REVENUE AND PUBLIC SUPPORT:											
Contributions	\$	256,735	\$ -	\$ 256,735	\$	160,198	\$ -	\$ 160,198			
Conference fees		235,544	-	235,544		316,682	-	316,682			
Fund contributions		-	38,223	38,223		-	97,336	97,336			
Subscription fees		-	-	-		702	-	702			
Interest and dividend income, net		24,334	17,257	41,591		13,565	17,789	31,354			
Net assets released from restrictions		410,255	(410,255)			84,454	(84,454)				
Total revenue		926,868	(354,775)	572,093		575,601	30,671	606,272			
FUNCTIONAL EXPENSES:											
Program and services		380,669	-	380,669		505,101	-	505,101			
Management and general		143,420	-	143,420		109,036	=	109,036			
Fundraising		28,959		28,959		42,187		42,187			
Total functional expenses		553,048		553,048		656,324		656,324			
Change in net assets before investment activity		373,820	(354,775)	19,045		(80,723)	30,671	(50,052)			
Net appreciation on investments		5,871	39,713	45,584		50,889	63,236	114,125			
CHANGE IN NET ASSETS		379,691	(315,062)	64,629		(29,834)	93,907	64,073			
NET ASSETS, Beginning of year		619,484	891,630	1,511,114		649,318	797,723	1,447,041			
NET ASSETS, End of year	\$	999,175	\$ 576,568	\$ 1,575,743	\$	619,484	\$ 891,630	\$ 1,511,114			

The accompanying notes are an integral part of this statement.

### <u>UNITED LEUKODYSTROPHY FOUNDATION, INC.</u> <u>STATEMENT OF CASH FLOWS</u> <u>FOR THE YEARS ENDED DECEMBER 31, 2024 AND 2023</u>

	2024	2023			
CASH FLOWS FROM OPERATING ACTIVITIES:					
Change in net assets	\$ 64,629	\$	64,073		
Adjustments to reconcile change in net assets	,		,		
(used in) provided by operating activities:					
Noncash portion of lease expense for operating lease	_		8,584		
Net realized and unrealized (gain) loss on investments	45,584		(114,125)		
Changes in assets and liabilities -			, , ,		
(Increase) decrease in prepaid expenses	(30,124)		500		
Increase (decrease) in accounts payable	(123)		358		
Increase (decrease) in accrued expenses	(9,123)		4,717		
(Decrease) in operating lease liability	 <u> </u>		(8,700)		
Net cash provided by (used in) operating activities	 70,843		(44,593)		
CASH FLOWS FROM INVESTING ACTIVITIES:					
Purchase of investments	(903,176)	(	1,208,877)		
Proceeds from sale of investments	 838,485		1,161,794		
Net cash (used in) investing activities	 (64,691)		(47,083)		
NET INCREASE (DECREASE) IN CASH	6,152		(91,676)		
CASH AND CASH EQUIVALENTS, Beginning of year	158,398		250,074		
CASH AND CASH EQUIVALENTS, End of year	\$ 164,550	\$	158,398		
NON-CASH INVESTMENT AND FINANCING ACTIVITES Right of use acquired through operating lease	\$ -	\$	8,488		

#### UNITED LEUKODYSTROPHY FOUNDATION, INC. STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED DECEMBER 31, 2024

Program Services Program Management Education Research Total and General Fundraising Total SALAIES AND RELATED EXPENSES 91,119 \$ 9,570 100,689 71,567 19,139 191,395 Salaries and wages Payroll taxes 8,642 908 9,550 6,788 1,815 18,153 290 206 Workers compensation 262 28 55 551 Total salaries and related expenses 100,023 10,506 110,529 78,561 21,009 210,099 PROGRAM EXPENSE Bank fees 3,076 162 3,238 Dues and subscription, and filing fees 4,820 4,820 3,944 8,764 Insurance 2,142 2,142 1,752 3,894 2,500 2,500 Miscellaneous 2,500 Postage 278 278 228 2,780 3,286 236 Printing and educational materials 289 525 289 Professional fees 21,523 21,523 18,650 2,563 42,736 Promotion and advertising 322 322 234 29 585 1,691 1,691 1,260 3,071 Supplies 120 Total program expenses 33,565 33,565 29,380 5,654 68,599 TECHNOLOGY 42,471 42,471 13,421 569 56,461 SPECIAL PROJECTS Benefit drawing and prizes 1,612 1,612 1,072 1,072 877 Newsletter 1,949 73,000 Research grant 73,000 73,000 1,072 73,000 74,072 877 1,612 76,561 Total special projects OCCUPANCY Rent 4,386 4,386 3,589 7,975 Utilities 3,220 3,220 2,635 5,855 7,606 6,224 13,830 Total occupancy 7,606 TRAVEL AND MEETING EXPENSES Travel 10,516 10,516 2,314 12,830 Other conference and meeting 101,910 101,910 12,643 115 114,668 Total travel and meeting expenses 112,426 112,426 14,957 115 127,498 TOTAL FUNCTIONAL EXPENSES 28,959 297,163 83,506 380,669 143,420 553,048

#### UNITED LEUKODYSTROPHY FOUNDATION, INC. STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED DECEMBER 31, 2023

	Program Services								
	Education	]	Research	I	Program Total	General	Fundraising		Total
SALAIES AND RELATED EXPENSES									
Salaries and wages	\$ 69,53	7 \$	16,536	\$	86,073	\$ 50,084	\$	15,128	\$ 151,285
Payroll taxes	6,483		1,542		8,025	4,669		1,410	14,104
Workers compensation	283	3	67		350	 205		62	 617
Total salaries and related expenses	76,300	3	18,145		94,448	 54,958		16,600	 166,006
PROGRAM EXPENSE									
Bank fees		-	-		-	-		2,154	2,154
Dues, subscription, and filing fees	579	)	105		684	4,758		4,495	9,937
Gifts		-	-		-	102		-	102
Insurance	2,010	5	367		2,383	1,100		183	3,666
Miscellaneous	2,500	)	_		2,500	_		_	2,500
Postage	550		5		555	16		2,856	3,427
Printing and educational materials	320		59		385	208		_	593
Professional fees	58,733		8,485		67,218	28,560		8,265	104,043
Promotion and advertising	2,069		376		2,445	1,714		188	4,347
Supplies	3,96		721		4,688	 2,077		361	 7,126
Total program expenses	70,740	)	10,118		80,858	38,535		18,502	 137,895
TECHNOLOGY	59,773	3	7,810		67,583	 9,977		542	 78,102
SPECIAL PROJECTS									
Benefit drawing and prizes		_	_		_	_		2,106	2,106
Newsletter	3,72	1	_		3,724	_		-,	3,724
Research grant			83,000		83,000	 			83,000
Total special projects	3,724	1	83,000		86,724	 		2,106	 88,830
OCCUPANCY									
Rent	5,48	7	998		6,485	2,992		499	9,976
Utilities	3,032	2	551		3,583	 1,654		276	 5,513
Total occupancy	8,519	)	1,549		10,068	 4,646		775	 15,489
TRAVEL AND MEETING EXPENSES									
Travel	4,122	2	-		4,122	282		3,557	7,961
Other conference and meeting	156,244	<u> </u>	5,054		161,298	 638		105	 162,041
Total travel and meeting expenses	160,360	5	5,054		165,420	 920		3,662	 170,002
TOTAL FUNCTIONAL EXPENSES	\$ 379,423	\$	125,676	\$	505,101	\$ 109,036	\$	42,187	\$ 656,324

# UNITED LEUKODYSTROPHY FOUNDATION, INC. NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2024 and 2023

#### (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 April 28, 2025, 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)

#### Investments -

The Organization carries investments in mutual funds and exchange-traded fund (ETF) with readily determined 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- for the years ended December 31, 2024 and 2023, 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 event fee price is set by the Organization. The Organization recognizes conference fee revenue when cash is received for the ticket to attend the 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- as of December 31, 2024 and 2023.

#### 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.

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

#### Revenue Recognition for Contributions - (Continued)

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. The Organization recognizes conference fee when cash is received for the ticket to attend the event.

#### Leases -

The Organization determines if an arrangement is a lease or contains a lease at inception of the contract. The Organization's operating leases 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, during 2024 the Organization renewed its only lease on a month to month basis.

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 leases 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, and 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 leases 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 leases 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.

#### 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 2021. The Organization does not expect a material net change in unrecognized tax benefits in the next twelve months.

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

#### 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, professional fees, insurance, 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:

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

<u>Level 2</u>: Inputs consist primarily of quoted prices for similar assets.

<u>Level 3</u>: 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.

The 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.

### (2) FAIR VALUE MEASUREMENTS: (Continued)

On December 31, 2024 and 2023, investments are stated at fair value and consist primarily of mutual funds as follows:

	2024									
	Level 1	Level 2	Level 3	Total						
Mutual Funds										
Fixed income	\$ 292,793	\$ -	\$ -	\$ 292,793						
Equities	610,929	-	_	610,929						
Alternative	97,509			97,509						
Total assets at fair value	\$ 1,001,231	<u>\$</u>	\$ -	\$ 1,001,231						
Cash equivalents at cost				379,012						
Total investments				\$ 1,380,243						
		20	023							
	Level 1	Level 2	Level 3	Total						
Mutual Funds										
Fixed income	\$ 587,146	\$ -	\$ -	\$ 587,146						
Equities	608,494	-	-	608,494						
Alternative	121,006			121,006						
Total assets at fair value	\$ 1,316,646	\$ -	<u>\$</u> -	1,316,646						
Cash equivalents at cost				44,490						
Total investments				<u>\$ 1,361,136</u>						

### (3) NET ASSETS WITH DONOR RESTRICTIONS:

Net assets with donor restrictions are restricted for the following purpose on December 31, 2024 and 2023:

		2024	 2023	
Program endowment	\$	-	\$ 133,524	
Research endowment		517,597	700,432	
Family Assistance endowment		58,971	 57,674	
Total net assets with donor restrictions	<u>\$</u>	576,568	\$ 891,630	

#### (4) CONCENTRATION OF CONTRIBUTION REVENUE:

For the year ended December 31, 2024, approximately 15% of total contributions came from two donors as a conference sponsorship.

#### (5) LEASES:

The Organization renewed its facility lease with a non-related party on month-to-month basis during 2024.

The components of lease expenses for the years ending December 31, 2024 and 2023, were as follows:

	2024		2023		
Operating lease cost Variable lease cost	\$	- <u>-</u>	\$	8,700 1,276	
Total lease expense	\$		\$	9,976	
The weighted average remaining lease term is as follows: Weighted average lease term		-		1 year	
Weighted average discount rate		-		5.41%	

Cash paid for amounts included in the measurements of the Organization's leases for the years ended December 31, 2024 and 2023 are as follows:

Operating cash from operating leases \$ - \$ 8,700

#### (6) ENDOWMENT:

The Organization's endowment consists of four endowment funds established to support research, family assistance, research initiatives and strategic initiatives funds. 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, 2024 and 2023, is as follows:

		2024					
	Without Donor Restrictions	With Donor Restrictions	Total				
Board-designated endowment funds	<u>\$ 803,675</u>	<u>\$</u> _	<u>\$ 803,675</u>				
Donor-restricted endowment funds: Accumulated investment earnings on amounts maintained in perpetuity		76,568	76,568				
Original donor-restricted gift amount and amounts required to be maintained in perpetuity by donor		500,000	500,000				
	<u>\$ 803,675</u>	\$ 576,568	\$ 1,380,243				
		2023					
	Without Donor Restrictions	2023 With Donor Restrictions	Total				
Board-designated endowment funds		With Donor	Total \$ 469,506				
Donor-restricted endowment funds: Accumulated investment earnings on amounts maintained in perpetuity	Restrictions	With Donor Restrictions					
Donor-restricted endowment funds: Accumulated investment earnings	Restrictions	With Donor Restrictions  \$ -	\$ 469,506				

#### (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, 2024 and 2023.

Changes in endowment net assets for the years ended December 31, 2024 and 2023, are as follows:

	Without Donor Restrictions	With Donor Restrictions	Total
Endowment net assets, beginning of year	\$ 469,506	\$ 891,630	\$ 1,361,136
Investment return:	24.224	17 257	41.501
Investment income Net appreciation (realized/unrealized)	24,334 5,871	17,257 39,713	41,591 45,584
Total investment return	30,205	56,970	87,175
Release from donor's restriction	344,032	(344,032)	<del>-</del>
Appropriated funds for expenditure	(40,068)	(28,000)	(68,068)
Endowment net assets, end of year	\$ 803,675	\$ 576,568	\$ 1,380,243
		2023	
	Without Donor Restrictions	2023 With Donor Restrictions	Total
Endowment net assets, beginning of year		With Donor	Total \$ 1,199,928
beginning of year  Investment return:	<u>Restrictions</u> \$ 402,205	With Donor Restrictions  \$ 797,723	\$ 1,199,928
beginning of year	Restrictions	With Donor Restrictions	
Investment return: Investment income	<u>Restrictions</u> \$ 402,205 13,565	With Donor Restrictions  \$ 797,723	\$ 1,199,928 31,354
beginning of year  Investment return: Investment income Net appreciation (realized/unrealized)	Restrictions  \$ 402,205  13,565 50,889	With Donor Restrictions  \$ 797,723  17,789 63,236	\$ 1,199,928 31,354 114,125
Investment return: Investment income Net appreciation (realized/unrealized)  Total investment return	Restrictions  \$ 402,205  13,565 50,889  64,454	With Donor Restrictions  \$ 797,723  17,789 63,236  81,025	\$ 1,199,928 31,354 114,125 145,479

#### (6) ENDOWMENT: (Continued)

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.

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:

	2024	2023
Financial assets - Cash and cash equivalents Investments	\$ 164,550 1,380,243	\$ 158,398 1,361,136
Total financial assets	1,544,793	1,519,534
Less amounts not available to be used within one year: Net assets with donor restriction Net assets with board designations	(576,568) (803,675) (1,380,243)	(891,630) (469,506) (1,361,136)
Financial assets available to meet cash needs for general expenditures: that is, without donor or other restrictions limiting their use within one year	<u>\$ 164,550</u>	<u>\$ 158,398</u>

### (7) LIQUIDITY AND AVAILABILITY: (Continued)

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, 2024 AND 2023

	2024					2023						
								Without Donor		r With Donor		
			Rest	trictions Total			Restrictions		Res	strictions		Total
GENERAL CONTRIBUTIONS												
Contributions	\$	256,735	\$		\$	256,735	\$	160,198	\$		\$	160,198
Total general contribution		256,735				256,735		160,198		<u>-</u>		160,198
CONFERENCES												
National conference fees		35,252		-		35,252		14,714		-		14,714
Sponsorships and exhibitors		185,948		-		185,948		286,938		-		286,938
Auction		14,344				14,344		15,030				15,030
Total conferences		235,544				235,544		316,682				316,682
FUND CONTRIBUTIONS												
ALD/AMN research		-		204		204		-		15,100		15,100
MLC research		-		1,250		1,250		-		785		785
MLD research		-		100		100		-		100		100
Krabbe research		-		1,717		1,717		-		4,800		4,800
Research fund (General)		-		28,339		28,339		-		41,204		41,204
Vanishing white matter research		-		225		225		-		30,000		30,000
Hultman memorial fund (Family Assistance)		-		5,413		5,413		-		3,501		3,501
Program fund				975		975				1,846		1,846
Total research contributions				38,223		38,223				97,336		97,336
MEMERHIPS												
Newsletter subscription						-		702				702
Total memberships								702				702
INTEREST AND DIVIDEND INCOME		24,334		17,257		41,591		13,565		17,789		31,354
TOTAL PUBLIC SUPPORT	\$	516,613	\$	55,480	\$	572,093	\$	491,147	\$	115,125	\$	606,272