

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

2025

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

Do not enter social security numbers on this form as it may be made public.

Go to www.irs.gov/Form990 for instructions and the latest information.

A For the 2025 calendar year, or tax year beginning , and ending

B Check if applicable:

☒ Address change☐ Name change☐ Initial return☐ Final return/terminated☐ Amended return☐ Application pending

C Name of organization UNITED LEUKODYSTROPHY FOUNDATION, INC.

Doing business as

Number and street (or P.O. box if mail is not delivered to street address)

1440 W TAYLOR ST

Room/suite

4297

City or town

CHICAGO

State

IL

ZIP code

60607

Foreign country name

Foreign province/state/county

Foreign postal code

D Employer identification number

35-1557361

E Telephone number

(815) 748-3211

G Gross receipts \$ 784,802

H(a) Is this a group return for subordinates? ☐ Yes ☒ NoH(b) Are all subordinates included? ☐ Yes ☐ No

If "No," attach a list. See instructions

H(c) Group exemption number

I Tax-exempt status: ☒ 501(c)(3) ☐ 501(c) () (insert no.) ☐ 4947(a)(1) or ☐ 527J Website: www.ulf.orgK Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other

L Year of formation: 1982

M State of legal domicile: IN

Part I Summary

Activities & Governance	1	Briefly describe the organization's mission or most significant activities: The United Leukodystrophy Foundation serves individuals and families affected by leukodystrophy by exchanging information and promoting progress on research, treatment and prevention.		
	2	Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3	Number of voting members of the governing body (Part VI, line 1a)	3	13
	4	Number of independent voting members of the governing body (Part VI, line 1b)	4	13
	5	Total number of individuals employed in calendar year 2025 (Part V, line 2a)	5	2
	6	Total number of volunteers (estimate if necessary)	6	
	7a	Total unrelated business revenue from Part VIII, column (C), line 12	7a	0
	b	Net unrelated business taxable income from Form 990-T, Part I, line 11	7b	
Revenue	8	Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9	Program service revenue (Part VIII, line 2g)	530,502	465,339
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	0	0
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	65,818	52,986
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	0	0
	12		596,320	518,325
Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	73,000	33,000
	14	Benefits paid to or for members (Part IX, column (A), line 4)	0	0
	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)	210,099	172,109
	16a	Professional fundraising fees (Part IX, column (A), line 11e)	0	0
	b	Total fundraising expenses (Part IX, column (D), line 25)		
	17	Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	24,749	
	17		269,949	277,489
	18	Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)	553,048	482,598
Net Assets or Fund Balances	19	Revenue less expenses. Subtract line 18 from line 12	43,272	35,727
	20	Total assets (Part X, line 16)	Beginning of Current Year	End of Year
	21	Total liabilities (Part X, line 26)	1,576,623	1,745,232
	22	Net assets or fund balances. Subtract line 21 from line 20	880	400
		1,575,743	1,744,832	

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here

Signature of officer

RON CHAPLEAU

Date

PRESIDENT

Type or print name and title

Paid Preparer Use Only

Preparer's name

J SCOTT CHILTON CPA

Preparer's signature

J Scott Chilton CPA

Date

4/28/2026

Check ☒ if self-employed

PTIN

P00299857

Firm's name J SCOTT CHILTON CPA

Firm's EIN 36-4019188

Firm's address 1013 N 1ST ST, DEKALB, IL 60115

Phone no. (815) 758-8141

May the IRS discuss this return with the preparer shown above? See instructions ☒ Yes ☐ No

For Paperwork Reduction Act Notice, see the separate instructions.

Form 990 (2025) Created 4/30/25

Part III**Statement of Program Service Accomplishments**Check if Schedule O contains a response or note to any line in this Part III ☐**1** Briefly describe the organization's mission:

The United Leukodystrophy Foundation is dedicated to helping children and adults who have Leukodystrophy and assisting family members, professionals and support services that serve them. The ULF is committed to the identification, treatment and cure of all leukodystrophies through programs of education, advocacy, research and service.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? ☐ Yes ☒ No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? ☐ Yes ☒ No

If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.**4a** (Code:) (Expenses \$ 381,430 including grants of \$ 33,000) (Revenue \$)

The United Leukodystrophy Foundation (ULF) is a nonprofit 501(c)3 organization founded in 1982 that serves patients, families and medical professionals in the U.S. and internationally. The ULF's mission is to provide support to the leukodystrophy community and enable platforms to accelerate improving patient quality of life and finding cures. Three of the ULF's main accomplishments include: 1) supporting leukodystrophy research to discover improved therapies and ultimately a cure; 2) presenting an annual educational scientific symposium and family conference; and 3) providing education and medical referrals to patients and families affected by the disease.

4b (Code:) (Expenses \$ including grants of \$) (Revenue \$)**4c** (Code:) (Expenses \$ including grants of \$) (Revenue \$)

4d Other program services (Describe on Schedule O.)
 (Expenses \$ 0 including grants of \$ 0) (Revenue \$ 0)

4e Total program service expenses 381,430

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A.</i>	X	
2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? See instructions.	X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I.</i>		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II.</i>		X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III.</i>		X
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I.</i>		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II.</i>		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III.</i>		X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV.</i>		X
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi-endowments? <i>If "Yes," complete Schedule D, Part V.</i>	X	
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI.</i>	X	
b Did the organization report an amount for investments—other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII.</i>		X
c Did the organization report an amount for investments—program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII.</i>		X
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX.</i>		X
e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X.</i>		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X.</i>		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII.</i>	X	
b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional.</i>		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E.</i>		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV.</i>		X
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV.</i>		X
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV.</i>		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I.</i> See instructions.		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II.</i>		X
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III.</i>		X
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H.</i>		X
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II.</i>	X	

Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III.</i>		X
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J.</i>		X
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a.</i>		X
24b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
24c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
24d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I.</i>		X
25b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I.</i>		X
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part II.</i>		X
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III.</i>		X
28 Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions).		
28a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV.</i>		X
28b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV.</i>		X
28c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV.</i>		X
29 Did the organization receive more than \$25,000 in noncash contributions? <i>If "Yes," complete Schedule M.</i>		X
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M.</i>		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I.</i>		X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II.</i>		X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I.</i>		X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1.</i>		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
35b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2.</i>		
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2.</i>		X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI.</i>		X
38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O.	X	

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V. ☐

	Yes	No
1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable.		
1b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable.		
1c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	X	

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

		Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return.	2a	2
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	X
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a	X
b	If "Yes," has it filed a Form 990-T for this year? If "No," to line 3b, provide an explanation on Schedule O.	3b	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a	X
b	If "Yes," enter the name of the foreign country See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b	X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c	
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?	6a	X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b	
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	X
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c	X
d	If "Yes," indicate the number of Forms 8282 filed during the year.	7d	
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e	X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f	X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g	
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h	
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	8	
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the sponsoring organization make any taxable distributions under section 4966?	9a	
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b	
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12.	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.	10b	
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders.	11a	
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year.	12b	
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.	13a	
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans.	13b	
c	Enter the amount of reserves on hand.	13c	
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a	X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O.	14b	
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see the instructions and file Form 4720, Schedule N.	15	X
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	16	X
17	Section 501(c)(21) organizations. Did the trust, or any disqualified or other person, engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? If "Yes," complete Form 6069.	17	

Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions. Check if Schedule O contains a response or note to any line in this Part VI. ☒

Section A. Governing Body and Management

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year. If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.	13	
1b	Enter the number of voting members included on line 1a, above, who are independent.	13	
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		X
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person?		X
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		X
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		X
6	Did the organization have members or stockholders?		X
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		X
7b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
8a	The governing body?	X	
8b	Each committee with authority to act on behalf of the governing body?	X	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O.		X

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

	Yes	No
10a		X
10b		
11a	X	
11b		
12a	X	
12b	X	
12c	X	
13	X	
14	X	
15a	X	
15b	X	
16a		X
16b		

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed See Attached Statement

18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
☐ Own website ☐ Another's website ☒ Upon request ☐ Other (explain on Schedule O)

19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.

20 State the name, address, and telephone number of the person who possesses the organization's books and records
RON CHAPLEAU (815) 748-3211
1440 W TAYLOR ST, STE 4247, CHICAGO, IL 60607

Part VII**Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**Check if Schedule O contains a response or note to any line in this Part VII ☐**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees****1a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See the instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See the instructions for the order in which to list the persons above.

☐ Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) Diane Fennimore Executive Director	40.00 0.00	X			X			96,595	0	
(2) Donna Skwirut Treasurer	2.00 0.00	X		X				0	0	
(3) Shannon Reed Secretary	2.00 0.00	X		X				0	0	
(4) Ron Chapleau President	15.00 0.00	X		X				0	0	
(5) Mousumi Bose Director	2.00 0.00	X						0	0	
(6) Amber Freed Director	2.00 0.00	X						0	0	
(7) Gregory Huffer Director	2.00 0.00	X						0	0	
(8) Dr. Joseph Hacia Director	2.00 0.00	X						0	0	
(9) Dr. Stephanie Keller Vice President	2.00 0.00	X		X				0	0	
(10) Marcie Flores Director	2.00 0.00	X						0	0	
(11) John Kaprich Director	2.00 0.00	X						0	0	
(12) Margaret McIntyre Director	2.00 0.00	X						0	0	
(13) Marilyn Schmiedel Director	2.00 0.00	X						0	0	
(14) Michele Herndon Director	2.00 0.00	X						0	0	

Part VII**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees** (continued)

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (VV-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (VV-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(15)										
(16)										
(17)										
(18)										
(19)										
(20)										
(21)										
(22)										
(23)										
(24)										
(25)										
1b Subtotal							96,595	0	0	
c Total from continuation sheets to Part VII, Section A							0	0	0	
d Total (add lines 1b and 1c)							96,595	0	0	

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 0

- 3** Did the organization list any **former** officer, director, trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual. 3
- 4** For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual. 4
- 5** Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person. 5

	Yes	No
3		X
4		X
5		X

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation
		0
		0
		0
		0
		0

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0

Part VIII**Statement of Revenue**Check if Schedule O contains a response or note to any line in this Part VIII. ☐

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns	1a 0				
	b	Membership dues	1b 0				
	c	Fundraising events	1c 0				
	d	Related organizations	1d 0				
	e	Government grants (contributions)	1e 0				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f 465,339				
	g	Noncash contributions included in lines 1a-1f	1g \$ 0				
	h	Total. Add lines 1a-1f	465,339				
	Program Service Revenue			Business Code			
2a		-----	0				
b		-----	0				
c		-----	0				
d		-----	0				
e		-----	0				
f		All other program service revenue	0				
g		Total. Add lines 2a-2f	0				
Other Revenue		3	Investment income (including dividends, interest, and other similar amounts)	35,376			35,376
	4	Income from investment of tax-exempt bond proceeds	0				
	5	Royalties	0				
	6a	Gross rents	(i) Real	(ii) Personal			
			6a				
			6b				
	c	Rental income or (loss)	6c 0	0			
	d	Net rental income or (loss)	0				
	7a	Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
			7a	0	284,087		
			7b	0	266,477		
	c	Gain or (loss)	7c 0	17,610			
	d	Net gain or (loss)	17,610			17,610	
	8a	Gross income from fundraising events (not including \$ of contributions reported on line 1c See Part IV, line 18	8a 0				
			8b 0				
	b	Less: direct expenses	0				
	c	Net income or (loss) from fundraising events	0				
	9a	Gross income from gaming activities. See Part IV, line 19	9a 0				
			9b 0				
	b	Less: direct expenses	0				
c	Net income or (loss) from gaming activities	0					
10a	Gross sales of inventory, less returns and allowances	10a 0					
		10b 0					
b	Less: cost of goods sold	0					
c	Net income or (loss) from sales of inventory	0					
Miscellaneous Revenue			Business Code				
	11a	-----	0				
	b	-----	0				
	c	-----	0				
	d	All other revenue	0				
	e	Total. Add lines 11a-11d	0				
12	Total revenue. See instructions	518,325	0	0	52,986		

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX. ☐

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.				
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	33,000	33,000		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	0			
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	0			
4 Benefits paid to or for members	0			
5 Compensation of current officers, directors, trustees, and key employees	0		0	
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0			
7 Other salaries and wages	156,651	117,488	31,330	7,833
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	0			
9 Other employee benefits	901	676	180	45
10 Payroll taxes	14,557	10,918	2,911	728
11 Fees for services (nonemployees):				
a Management	6,489	3,296	2,414	779
b Legal	0			
c Accounting	15,595	7,922	5,801	1,872
d Lobbying	0			
e Professional fundraising services. See Part IV, line 17	0			
f Investment management fees	0			
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Schedule O.)	29,231	14,849	10,874	3,508
12 Advertising and promotion	300	285		15
13 Office expenses	14,253	6,721	2,357	5,175
14 Information technology	60,249	55,318	4,240	691
15 Royalties	0			
16 Occupancy	10,679	6,941	3,203	535
17 Travel	0			
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0			
19 Conferences, conventions, and meetings	124,915	124,016	642	257
20 Interest	0			
21 Payments to affiliates	0			
22 Depreciation, depletion, and amortization	0	0	0	0
23 Insurance	4,475		4,251	224
24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule O.)				
a Dues, Subscriptions & Filing Fees	8,648		8,216	432
b Staff Education	0			
c Special Projects	2,655			2,655
d	0			
e All other expenses	0			
25 Total functional expenses. Add lines 1 through 24e	482,598	381,430	76,419	24,749
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☐ if following SOP 98-2 (ASC 958-720)				

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part X. ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	164,550	1	182,564
	2 Savings and temporary cash investments	0	2	
	3 Pledges and grants receivable, net	0	3	0
	4 Accounts receivable, net	0	4	0
	5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons	0	5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)	0	6	
	7 Notes and loans receivable, net	0	7	0
	8 Inventories for sale or use	0	8	
	9 Prepaid expenses and deferred charges	31,830	9	26,097
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 21,003		
	b Less: accumulated depreciation	10b 21,003	0	10c 0
	11 Investments—publicly traded securities	1,380,243	11	1,536,571
	12 Investments—other securities. See Part IV, line 11	0	12	0
	13 Investments—program-related. See Part IV, line 11	0	13	0
	14 Intangible assets	0	14	0
	15 Other assets. See Part IV, line 11	0	15	0
16 Total assets. Add lines 1 through 15 (must equal line 33)	1,576,623	16	1,745,232	
Liabilities	17 Accounts payable and accrued expenses	880	17	400
	18 Grants payable	0	18	
	19 Deferred revenue	0	19	
	20 Tax-exempt bond liabilities	0	20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D	0	21	
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons	0	22	
	23 Secured mortgages and notes payable to unrelated third parties	0	23	0
	24 Unsecured notes and loans payable to unrelated third parties	0	24	0
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17–24). Complete Part X of Schedule D	0	25	0
	26 Total liabilities. Add lines 17 through 25	880	26	400
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	999,175	27	1,101,549
	28 Net assets with donor restrictions	576,568	28	643,283
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds	0	29	
	30 Paid-in or capital surplus, or land, building, or equipment fund	0	30	
	31 Retained earnings, endowment, accumulated income, or other funds	0	31	
	32 Total net assets or fund balances	1,575,743	32	1,744,832
33 Total liabilities and net assets/fund balances	1,576,623	33	1,745,232	

Part XI Reconciliation of Net AssetsCheck if Schedule O contains a response or note to any line in this Part XI. ☐

1	Total revenue (must equal Part VIII, column (A), line 12)	1	518,325
2	Total expenses (must equal Part IX, column (A), line 25)	2	482,598
3	Revenue less expenses. Subtract line 2 from line 1	3	35,727
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,575,743
5	Net unrealized gains (losses) on investments	5	133,362
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	1,744,832

Part XII Financial Statements and ReportingCheck if Schedule O contains a response or note to any line in this Part XII. ☐

	Yes	No
1 Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both. ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		X
b Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both. ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	X	
c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	X	
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		X
b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A
(Form 990)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

Attach to Form 990 or Form 990-EZ.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2025

Open to Public
Inspection

Name of the organization

UNITED LEUKODYSTROPHY FOUNDATION, INC.

Employer identification number

35-1557361

Part I Reason for Public Charity Status. (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2 ☐ A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990).)
- 3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: _____
- 5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7 ☒ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8 ☐ A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9 ☐ An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: _____
- 10 ☐ An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11 ☐ An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**. Check the box on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
- a ☐ **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
- b ☐ **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
- c ☐ **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
- d ☐ **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization must generally satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
- e ☐ Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
- f Enter the number of supported organizations 0
- g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
(A)						
(B)						
(C)						
(D)						
(E)						
Total					0	0

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2021	(b) 2022	(c) 2023	(d) 2024	(e) 2025	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	570,742	567,746	574,918	530,502	465,339	2,709,247
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0
3 The value of services or facilities furnished by a governmental unit to the organization without charge						0
4 Total. Add lines 1 through 3	570,742	567,746	574,918	530,502	465,339	2,709,247
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						122,625
6 Public support. Subtract line 5 from line 4						2,586,622

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2021	(b) 2022	(c) 2023	(d) 2024	(e) 2025	(f) Total
7 Amounts from line 4	570,742	567,746	574,918	530,502	465,339	2,709,247
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	43,130	37,387	31,354	41,591	35,376	188,838
9 Net income from unrelated business activities, whether or not the business is regularly carried on						0
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						0
11 Total support. Add lines 7 through 10						2,898,085
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2025 (line 6, column (f), divided by line 11, column (f))	14	89.25%
15 Public support percentage from 2024 Schedule A, Part II, line 14	15	91.17%
16a 33 1/3% support test—2025. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		☒
b 33 1/3% support test—2024. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		☐
17a 10%-facts-and-circumstances test—2025. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		☐
b 10%-facts-and-circumstances test—2024. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		☐
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions		☐

Schedule B
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Schedule of Contributors

Attach to Form 990, 990-EZ, or 990-PF.

Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

Name of the organization

UNITED LEUKODYSTROPHY FOUNDATION, INC.

Employer identification number

35-1557361

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

☒ 501(c)(3) (enter number) organization

☐ 4947(a)(1) nonexempt charitable trust **not** treated as a private foundation

☐ 527 political organization

Form 990-PF

☐ 501(c)(3) exempt private foundation

☐ 4947(a)(1) nonexempt charitable trust treated as a private foundation

☐ 501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**.

Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

- ☐ For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

- ☒ For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3 % support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

- ☐ For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.

- ☐ For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year \$

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990).

Name of organization

UNITED LEUKODYSTROPHY FOUNDATION, INC.

Employer identification number

35-1557361

Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	Ionis Pharmaceuticals 2855 Gazelle Court Carlsbad CA 92010 Foreign State or Province: Foreign Country:	\$ 25,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
2	Minoryx Therapeutics Mataro, E-08302 Barcelona Foreign State or Province: Mataro Foreign Country: Spain	\$ 14,950	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
3	Vigil Neuroscience Inc 300 Technology Square 8th Fl Cambridge MA 02139 Foreign State or Province: Foreign Country:	\$ 35,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
4	Orchard Therapeutics 2 Seaport Ln, 8th Floor Boston MA 02210 Foreign State or Province: Foreign Country:	\$ 45,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
5	Mirum Pharmaceuticals, Inc. 989 E Hillsdale Ave, Suite 300 Foster City CA 94404 Foreign State or Province: Foreign Country:	\$ 40,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
6	Kent Richter 12207 Lakeside Ln Tavares FL 32778 Foreign State or Province: Foreign Country:	\$ 10,050	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)

Name of organization UNITED LEUKODYSTROPHY FOUNDATION, INC.	Employer identification number 35-1557361
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Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	Calico Life Sciences, LLC 1130 Veterans Blvd South San Francisco CA 94080 Foreign State or Province: _____ Foreign Country: _____	\$ 10,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
8	Bruce & Elena Borchardt 10041 Sunrise Ln Santa Ana CA 92705 Foreign State or Province: _____ Foreign Country: _____	\$ 10,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
9	Aspa Therapeutics, Inc 3160 Porter Dr Ste 250 Palo Alto CA 94304 Foreign State or Province: _____ Foreign Country: _____	\$ 15,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
10	AbbVie N. Waukegan Rd North Chicago IL 60064 Foreign State or Province: _____ Foreign Country: _____	\$ 10,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
11	The TJX Companies, Inc 770 Cochituate Rd Framingham MA 01701 Foreign State or Province: _____ Foreign Country: _____	\$ 10,000	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
	_____ _____ _____ Foreign State or Province: _____ Foreign Country: _____	\$ _____	Person ☐ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)

SCHEDULE D
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

Complete if the organization answered "Yes" on Form 990,
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.
Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization

UNITED LEUKODYSTROPHY FOUNDATION, INC.

Employer identification number

35-1557361

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts

Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		
5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?		☐ Yes ☐ No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?		☐ Yes ☐ No

Part II Conservation Easements

Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1 Purpose(s) of conservation easements held by the organization (check all that apply): ☐ Preservation of land for public use (for example, recreation or education) ☐ Protection of natural habitat ☐ Preservation of open space ☐ Preservation of a historically important land area ☐ Preservation of a certified historic structure	
2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.	Held at the End of the Tax Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included on line 2a	2c
d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register	2d
3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year	
4 Number of states where property subject to conservation easement is located	
5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?	☐ Yes ☐ No
6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year	
7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year	\$
8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?	☐ Yes ☐ No
9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.	

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.	
b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items.	
(i) Revenue included on Form 990, Part VIII, line 1	\$
(ii) Assets included in Form 990, Part X	\$
2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items.	
a Revenue included on Form 990, Part VIII, line 1	\$
b Assets included in Form 990, Part X	\$

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

3 Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply).

a ☐ Public exhibition

d ☐ Loan or exchange program

b ☐ Scholarly research

e ☐ Other

c ☐ Preservation for future generations

4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? ☐ Yes ☐ No

Part IV Escrow and Custodial Arrangements

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a Is the organization an agent, trustee, custodian, or other intermediary for contributions or other assets not included on Form 990, Part X? ☐ Yes ☐ No

b If "Yes," explain the arrangement in Part XIII and complete the following table.

c Beginning balance

d Additions during the year

e Distributions during the year

f Ending balance

	Amount
1c	0
1d	
1e	
1f	0

2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? ☐ Yes ☒ No

b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII ☐

Part V Endowment Funds

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	1,380,243	1,361,136	1,199,928	1,392,526	931,328
b Contributions			71,228	55,235	371,493
c Net investment earnings, gains, and losses		44,107	145,480	-192,833	114,168
d Grants or scholarships		25,000	53,000	53,000	15,000
e Other expenditures for facilities and programs			2,500	2,000	9,463
f Administrative expenses					
g End of year balance	1,380,243	1,380,243	1,361,136	1,199,928	1,392,526

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

a Board designated or quasi-endowment 58%

b Permanent endowment 42%

c Term endowment %

The percentages on lines 2a, 2b, and 2c should equal 100%.

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

(i) Unrelated organizations

(ii) Related organizations

	Yes	No
3a(i)		X
3a(ii)		X
3b		

b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?

4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land	0	0		0
b Buildings	0	0	0	0
c Leasehold improvements	0	0	0	0
d Equipment	0	21,003	21,003	0
e Other	0	0	0	0

Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B)). 0

Part VII Investments—Other Securities

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives	0	
(2) Closely held equity interests	0	
(3) Other		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Column (b) must equal Form 990, Part X, line 12, col. (B)).	0	

Part VIII Investments—Program Related

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
Total. (Column (b) must equal Form 990, Part X, line 13, col. (B)).	0	

Part IX Other Assets

Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, line 15, col. (B)).	0

Part X Other Liabilities

Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

(a) Description of liability	(b) Book value
1. (1) Federal income taxes	0
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, line 25, col. (B)).	0

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII . . . ☐

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	651,687
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	133,362	
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	133,362
3	Subtract line 2e from line 1		3	518,325
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	0
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)		5	518,325

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	482,598
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a		
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	0
3	Subtract line 2e from line 1		3	482,598
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	0
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)		5	482,598

Part XIII Supplemental Information

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

Part XIII Supplemental Information *(continued)*

Electronic Filing Only

SCHEDULE I
(Form 990)

Rev. December 2024)

Department of the Treasury
Internal Revenue Service
Name of the organization

Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Employer identification number

35-1557361

UNITED LEUKODYSTROPHY FOUNDATION, INC.

Part I General Information on Grants and Assistance

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☒ Yes ☐ No
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) UMass Chan Medical School 55 Lake Ave N Worcester, MA 01655-0	04-3167352		33,000				Research
(2) _____							
(3) _____							
(4) _____							
(5) _____							
(6) _____							
(7) _____							
(8) _____							
(9) _____							
(10) _____							
(11) _____							
(12) _____							

- 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table 1
- 3 Enter total number of other organizations listed in the line 1 table 1

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) (Rev. 12-2024)

Part III

Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22. Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
1					
2					
3					
4					
5					
6					
7					

Part IV

Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

SCHEDULE O
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.

Attach to Form 990 or Form 990-EZ.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

**Open to Public
Inspection**

Name of the organization

Employer identification number

UNITED LEUKODYSTROPHY FOUNDATION, INC.

35-1557361

Form 990, Part VI, Section B, Line 11b: - The Foundation Form 990 was prepared by its Accountant, ULF Staff and Board members. A copy of the complete Form 990 was e-mailed to the ULF and reviewed by the Finance Committee (which includes, but is not necessarily limited to, the Board President, Treasurer, Executive Director with assistance from the Financial and Operations Coordinator). The Finance Committee members reviewed the entire form and if adjustments might be needed, reached out to the Accountant to discuss and assess.

Form 990, Part VI, Section B, Line 12c: - The Foundation regularly and consistently monitors and enforces compliance with its conflict of interest policy by considering any real or potential conflicts prior to any voting among the board in official meetings. Members are asked if there are any conflicts if it is not known based on previous disclosure documentation.

Form 990, Part VI, Section B, Line 15a/b: - The compensation of the organization's key employees are set by the Board of Directors. The Board uses data as to comparable compensation for similarly qualified persons in functionally comparable positions at similarly situated organizations when setting compensation amounts. The same procedures are used for all other employees.

Form 990, Part VI, Section C, Line 19: - The organization makes its governing documents, conflict of interest policy and financial statements available to the public. All of these documents are available upon request to anyone at anytime.

Electronic Filing Only

Part VI, Line 17 (990) - States with Which a Copy of this Form 990 is Required to be Filed

☐	Armed Forces the Americas	☐	Louisiana	☐	Palau
☐	Armed Forces Europe	☒	Massachusetts	☐	Rhode Island
☐	Alaska	☒	Maryland	☒	South Carolina
☐	Alabama	☐	Maine	☐	South Dakota
☐	Armed Forces Pacific	☐	Marshall Islands	☒	Tennessee
☐	Arkansas	☒	Michigan	☒	Texas
☐	American Samoa	☒	Minnesota	☐	Utah
☐	Arizona	☐	Missouri	☒	Virginia
☒	California	☐	Commonwealth of the Northern Mariana Islands	☐	U.S. Virgin Islands
☐	Colorado	☐	Mississippi	☒	Vermont
☒	Connecticut	☐	Montana	☒	Washington
☐	District of Columbia	☒	North Carolina	☒	Wisconsin
☐	Delaware	☐	North Dakota	☐	West Virginia
☒	Florida	☐	Nebraska	☐	Wyoming
☐	Federated States of Micronesia	☒	New Hampshire		
☒	Georgia	☒	New Jersey		
☐	Guam	☐	New Mexico		
☐	Hawaii	☐	Nevada		
☐	Iowa	☒	New York		
☐	Idaho	☒	Ohio		
☒	Illinois	☒	Oklahoma		
☒	Indiana	☒	Oregon		
☐	Kansas	☒	Pennsylvania		
☐	Kentucky	☐	Puerto Rico		