

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2021

Open to Public Inspection

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

Department of the Treasury

Internal Revenue Service

For the 2021 calendar year, or tax year beginning 01-01-2022, and ending 12-31-2022

- 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): 224 N SECOND ST. Room/suite: City or town, state or province, country, and ZIP or foreign postal code: DEKALB, IL 60115

D Employer identification number: 35-1557361. E Telephone number: (815) 748-3211. G Gross receipts \$ 3,258,760

F Name and address of principal officer: RON CHAPLEAU, 224 N SECOND ST, DEKALB, IL 60115

H(a) Is this a group return for subordinates? No. H(b) Are all subordinates included? No. H(c) Group exemption number

I Tax-exempt status: 501(c)(3)

J Website: www.ulf.org

K Form of organization: Corporation

L Year of formation: 1982. M State of legal domicile: IN

Part I Summary

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.

Table with 2 columns: Description and Amount. Rows include: 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 (14). 4 Number of independent voting members of the governing body (14). 5 Total number of individuals employed in calendar year 2021 (3). 6 Total number of volunteers (estimate if necessary). 7a Total unrelated business revenue from Part VIII, column (C), line 12 (0). 7b Net unrelated business taxable income from Form 990-T, Part I, line 11.

Table with 3 columns: Description, Prior Year, Current Year. Rows include: 8 Contributions and grants (570,742 / 567,746). 9 Program service revenue (0). 10 Investment income (90,271 / -74,035). 11 Other revenue (1,649 / 5,186). 12 Total revenue—add lines 8 through 11 (662,662 / 498,897). 13 Grants and similar amounts paid (68,000 / 84,940). 14 Benefits paid to or for members (0). 15 Salaries, other compensation, employee benefits (159,535 / 188,757). 16a Professional fundraising fees (0). 16b Total fundraising expenses (78,874). 17 Other expenses (209,655 / 284,084). 18 Total expenses. Add lines 13-17 (437,190 / 557,781). 19 Revenue less expenses. Subtract line 18 from line 12 (225,472 / -58,884).

Table with 3 columns: Description, Beginning of Current Year, End of Year. Rows include: 20 Total assets (1,641,493 / 1,456,386). 21 Total liabilities (16,771 / 9,345). 22 Net assets or fund balances. Subtract line 21 from line 20 (1,624,722 / 1,447,041).

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 PRESIDENT. Date: 2023-05-22. Type or print name and title.

Paid Preparer Use Only: Print/Type preparer's name: J SCOTT CHILTON CPA. Preparer's signature. Date: 2023-05-22. Check if self-employed. PTIN: P00299857. 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

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 \$ 358,276 including grants of \$ 84,940) (Revenue \$)
The United Leukodystrophy Foundation ULF is a nonprofit 501c3 organization founded in 1982 that serves patients, families and medical professionals in the U.S. and internationally. The ULFs 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 ULFs 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 in Schedule O.) (Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 358,276

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>	Yes	
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? See instructions.	Yes	
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>		No
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>		No
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>		No
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>		No
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>		No
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>		No
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>		No
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi endowments? <i>If "Yes," complete Schedule D, Part V</i>	Yes	
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>	Yes	
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>		No
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>		No
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>		No
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>		No
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)?		No
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>	Yes	
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>		No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		No
14a	Did the organization maintain an office, employees, or agents outside of the United States?		No
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>	Yes	
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>	Yes	
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>		No
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.		No
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>		No
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>		No
20a	Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		No
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>	Yes	

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>	22	No
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>	23	No
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>	24a	No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b	
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c	
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d	
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>	25a	No
b	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>	25b	No
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?	26	No
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>	27	No
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):		
a	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>	28a	No
b	A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>	28b	No
c	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>	28c	No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29	No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions?	30	No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31	No
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>	32	No
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?	33	No
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>	34	No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a	No
b	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>	35b	
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>	36	No
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>	37	No
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.	38	Yes

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check 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	1a	2
b	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable	1b	0
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	Yes

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

<p>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</p>	<p>2a</p>	<p>3</p>			
<p>b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. See instructions.</p>	<p>2b</p>	<p>Yes</p>			
<p>3a Did the organization have unrelated business gross income of \$1,000 or more during the year?</p>	<p>3a</p>		<p>No</p>		
<p>b If "Yes," has it filed a Form 990-T for this year?<i>If "No" to line 3b, provide an explanation in Schedule O</i></p>	<p>3b</p>				
<p>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)?</p>	<p>4a</p>		<p>No</p>		
<p>b Enter the name of the foreign country: _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).</p>					
<p>5a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?</p>	<p>5a</p>		<p>No</p>		
<p>b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?</p>	<p>5b</p>		<p>No</p>		
<p>c If "Yes," to line 5a or 5b, did the organization file Form 8886-T?</p>	<p>5c</p>				
<p>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?</p>	<p>6a</p>		<p>No</p>		
<p>b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?</p>	<p>6b</p>				
<p>7 Organizations that may receive deductible contributions under section 170(c).</p>					
<p>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?</p>	<p>7a</p>		<p>No</p>		
<p>b If "Yes," did the organization notify the donor of the value of the goods or services provided?</p>	<p>7b</p>				
<p>c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?</p>	<p>7c</p>		<p>No</p>		
<p>d If "Yes," indicate the number of Forms 8282 filed during the year</p>	<p>7d</p>				
<p>e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?</p>	<p>7e</p>		<p>No</p>		
<p>f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?</p>	<p>7f</p>		<p>No</p>		
<p>g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?</p>	<p>7g</p>				
<p>h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?</p>	<p>7h</p>				
<p>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?</p>	<p>8</p>				
<p>9 Sponsoring organizations maintaining donor advised funds.</p>					
<p>a Did the sponsoring organization make any taxable distributions under section 4966?</p>	<p>9a</p>				
<p>b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?</p>	<p>9b</p>				
<p>10 Section 501(c)(7) organizations. Enter:</p>					
<p>a Initiation fees and capital contributions included on Part VIII, line 12</p>	<p>10a</p>				
<p>b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities</p>	<p>10b</p>				
<p>11 Section 501(c)(12) organizations. Enter:</p>					
<p>a Gross income from members or shareholders</p>	<p>11a</p>				
<p>b Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)</p>	<p>11b</p>				
<p>12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?</p>					
<p>b If "Yes," enter the amount of tax-exempt interest received or accrued during the year.</p>	<p>12b</p>				
<p>13 Section 501(c)(29) qualified nonprofit health insurance issuers.</p>					
<p>a Is the organization licensed to issue qualified health plans in more than one state?</p>	<p>13a</p>				
<p>Note. See the instructions for additional information the organization must report on Schedule O.</p>					
<p>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</p>	<p>13b</p>				
<p>c Enter the amount of reserves on hand</p>	<p>13c</p>				
<p>14a Did the organization receive any payments for indoor tanning services during the tax year?</p>	<p>14a</p>		<p>No</p>		
<p>b If "Yes," has it filed a Form 720 to report these payments?<i>If "No," provide an explanation in Schedule O</i></p>	<p>14b</p>				
<p>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?</p>	<p>15</p>		<p>No</p>		
<p>16 If the organization is a trust, did it file Form 720, Schedule E, to report the section 4968 excise tax on net investment income?</p>	<p>16</p>		<p>No</p>		
<p>If "Yes," complete Form 4720, Schedule O.</p>					
<p>17 Section 501(c)(21) organizations. Did the trust, any disqualified person, or mine operator engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953?</p>	<p>17</p>				
<p>If "Yes," complete Form 6069.</p>					

Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in 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

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members included... 2 Did any officer, director, trustee, or key employee have a family relationship... 3 Did the organization delegate control over management duties... 4 Did the organization make any significant changes to its governing documents... 5 Did the organization become aware during the year of a significant diversion of the organization's assets... 6 Did the organization have members or stockholders... 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? 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a The governing body? 8b Each committee with authority to act on behalf of the governing body? 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 in Schedule O.

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates? 10b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11b Describe on Schedule O the process, if any, used by the organization to review this Form 990. 12a Did the organization have a written conflict of interest policy? If "No," go to line 13 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done 13 Did the organization have a written whistleblower policy? 14 Did the organization have a written document retention and destruction policy? 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? 15a The organization's CEO, Executive Director, or top management official 15b Other officers or key employees of the organization If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? 16b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?

Section C. Disclosure

Table with 3 columns: Question, Yes, No. Rows include: 17 List the states with which a copy of this Form 990 is required to be filed CA, CT, FL, GA, IL, IN, MA, MD, MI, MN, NC, NH, NJ, NY, OH, OK, OR, PA, SC, TN, TX, VA, VT, WA, WI 18 Section 6104 requires an organization to make its Form 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 in Schedule O) 19 Describe in 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 224 N SECOND ST STE 2 DEKALB, IL 60115 (815) 748-3211

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, 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, or 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) Christopher Rice Executive Director	40.00	X			X			61,092	0	0
(2) Donna Skwirut Treasurer	2.00	X		X				0	0	0
(3) Sa Von Rudenick Secretary	2.00	X		X				0	0	0
(4) Ron Chapleau Vice President	2.00	X		X				0	0	0
(5) John Wolf Director	2.00	X						0	0	0
(6) Robert Rauner President	15.00	X		X				0	0	0
(7) Joyce Changle Director	2.00	X						0	0	0
(8) Kristie DeMarco Director	2.00	X						0	0	0
(9) Dr Joseph Hacia Director	2.00	X						0	0	0
(10) Dr Stephanie Keller Director	2.00	X						0	0	0
(11) Marcie Flores Director	2.00	X						0	0	0
(12) John Kaprich Director	2.00	X						0	0	0
(13) Margaret Mcintyre Director	2.00	X						0	0	0
(14) Shannon Reed Director	2.00	X						0	0	0
(15) Marilyn Schmiedel Director	2.00	X						0	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 (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			
1b Sub-Total										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)							61,092			

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 ▶

	Yes	No
3 Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		No
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? <i>If "Yes," complete Schedule J for such individual</i>		No
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		No

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

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 ▶

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					
	b Membership dues . . .	1b	4,486				
	c Fundraising events . . .	1c					
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above	1f	563,260				
	g Noncash contributions included in lines 1a - 1f:\$	1g					
	h Total. Add lines 1a-1f		567,746				
Program Service Revenue	2a	Business Code					
	b						
	c						
	d						
	e						
	f All other program service revenue.						
	g Total. Add lines 2a-2f.						
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		37,387			37,387	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6a Gross rents	(i) Real	(ii) Personal				
		6b Less: rental expenses					
		6c Rental income or (loss)					
	d Net rental income or (loss)						
	7a Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other	2,638,926			
		7b Less: cost or other basis and sales expenses		2,750,348			
		7c Gain or (loss)		-111,422			
	d Net gain or (loss)		-111,422				
	8a Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18						
		8b Less: direct expenses					
		c Net income or (loss) from fundraising events					
	9a Gross income from gaming activities. See Part IV, line 19						
9b Less: direct expenses							
c Net income or (loss) from gaming activities							
10a Gross sales of inventory, less returns and allowances			14,701				
	10b Less: cost of goods sold		9,515				
	c Net income or (loss) from sales of inventory		5,186				
Miscellaneous Revenue	Business Code						
11a							
b							
c							
d All other revenue							
e Total. Add lines 11a-11d							
12 Total revenue. See instructions			498,897			37,387	

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	20,000	20,000		
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.	64,940	64,940		
4 Benefits paid to or for members	0			
5 Compensation of current officers, directors, trustees, and key employees	61,092	12,218	30,546	18,328
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	110,903	22,181	55,452	33,270
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	0			
9 Other employee benefits	1,505	673	430	402
10 Payroll taxes	15,257	6,820	4,364	4,073
11 Fees for services (non-employees):				
a Management	4,000	1,044	2,768	188
b Legal	0			
c Accounting	17,126	4,470	11,851	805
d Lobbying	0			
e Professional fundraising services. See Part IV, line 17				
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)	836	218	579	39
12 Advertising and promotion	3,811	3,811		
13 Office expenses	18,293	8,812	2,689	6,792
14 Information technology	53,681	44,264	6,341	3,076
15 Royalties	0			
16 Occupancy	13,633	6,086	3,912	3,635
17 Travel	0			
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0			
19 Conferences, conventions, and meetings	158,469	158,078	391	
20 Interest	0			
21 Payments to affiliates	0			
22 Depreciation, depletion, and amortization	0			
23 Insurance	3,524	1,575	1,008	941
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in 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	8,257	632	300	7,325
b Special Projects	2,454	2,454		
c				
d				
e All other expenses	0			
25 Total functional expenses. Add lines 1 through 24e	557,781	358,276	120,631	78,874
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 <input type="checkbox"/> if following SOP 98-2 (ASC 958-720).				

Part X Balance Sheet

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

		(A) Beginning of year		(B) End of year
Assets	1 Cash-non-interest-bearing	241,727	1	250,074
	2 Savings and temporary cash investments		2	
	3 Pledges and grants receivable, net		3	
	4 Accounts receivable, net		4	
	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		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)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	7,240	9	2,206
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	21,003		
	b Less: accumulated depreciation	21,003	10c	
	11 Investments—publicly traded securities	1,392,526	11	1,199,928
	12 Investments—other securities. See Part IV, line 11		12	
	13 Investments—program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11		15	4,178
16 Total assets: Add lines 1 through 15 (must equal line 33)	1,641,493	16	1,456,386	
Liabilities	17 Accounts payable and accrued expenses	16,771	17	9,345
	18 Grants payable		18	
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		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		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	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		25	
	26 Total liabilities: Add lines 17 through 25	16,771	26	9,345
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	719,537	27	649,318
	28 Net assets with donor restrictions	905,185	28	797,723
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	1,624,722	32	1,447,041
33 Total liabilities and net assets/fund balances	1,641,493	33	1,456,386	

Part XI Reconciliation of Net Assets

Check 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	498,897
2	Total expenses (must equal Part IX, column (A), line 25)	2	557,781
3	Revenue less expenses. Subtract line 2 from line 1	3	-58,884
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,624,722
5	Net unrealized gains (losses) on investments	5	-118,797
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 in 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 (A))	10	1,447,041

Part XII Financial Statements and Reporting

Check 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: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> 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: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
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: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
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 in Schedule O.	Yes	
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		No
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 in Schedule O and describe any steps taken to undergo such audits.		

Additional Data

[Return to Form](#)

Software ID: 22015461

Software Version: 22.0.1.0

Form 990, Special Condition Description:

Special Condition Description

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.

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 **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 generally must 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 _____
 - 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		
Total						

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 failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	385,608	391,066	650,492	570,742	567,746	2,565,654
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge..						
4 Total. Add lines 1 through 3	385,608	391,066	650,492	570,742	567,746	2,565,654
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) . . .						559,437
6 Public support. Subtract line 5 from line 4.						2,006,217

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
7 Amounts from line 4.	385,608	391,066	650,492	570,742	567,746	2,565,654
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	27,837	22,069	19,386	43,130	37,387	149,809
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11 Total support. Add lines 7 through 10						2,715,463

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 2022 (line 6, column (f) divided by line 11, column (f))	14	73.880 %
15 Public support percentage for 2020 Schedule A, Part II, line 14	15	73.080 %

16a 33 1/3% support test—2022. 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—2021. 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—2022. 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—2021. 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

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Table with 7 columns: (a) 2018, (b) 2019, (c) 2020, (d) 2021, (e) 2022, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 8 Public support.

Section B. Total Support

Table with 7 columns: (a) 2018, (b) 2019, (c) 2020, (d) 2021, (e) 2022, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 11 Net income from unrelated business activities not included on line 10b; 12 Other income; 13 Total support; 14 First 5 years.

Section C. Computation of Public Support Percentage

Table with 2 columns: Description, Percentage. Row 15: Public support percentage for 2022 (line 8, column (f) divided by line 13, column (f)). Row 16: Public support percentage from 2021 Schedule A, Part III, line 15.

Section D. Computation of Investment Income Percentage

Table with 2 columns: Description, Percentage. Row 17: Investment income percentage for 2022 (line 10c, column (f) divided by line 13, column (f)). Row 18: Investment income percentage from 2021 Schedule A, Part III, line 17.

- 19a 33 1/3% support tests-2022. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here.
b 33 1/3% support tests-2021. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here.
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions.

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, of Part I, complete Sections A and B. If you checked box 12b, of Part I, complete Sections A and C. If you checked box 12c, of Part I, complete Sections A, D, and E. If you checked box 12d, of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

		Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.		
b	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the organization made the determination.		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
c	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).		
b	Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c	Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI .		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990).		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? If "Yes," complete Part I of Schedule L (Form 990).		
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI .		
b	Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in Part VI .		
c	Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI .		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.		
b	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).		

Part IV Supporting Organizations (continued)

		Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?		
a	A person who directly or indirectly controls, either alone or together with persons described on lines 11b and 11c below, the governing body of a supported organization?		
b	A family member of a person described on 11a above?		
c	A 35% controlled entity of a person described on line 11a or 11b above? <i>If "Yes" to 11a, 11b, or 11c, provide detail in Part VI</i>		

Section B. Type I Supporting Organizations

		Yes	No
1	Did the officers, directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
2	Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

		Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

		Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
3	By reason of the relationship described in line 2 above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions):

- a** The organization satisfied the Activities Test. Complete **line 2** below.
- b** The organization is the parent of each of its supported organizations. Complete **line 3** below.
- c** The organization supported a governmental entity. Describe in **Part VI** how you supported a government entity (see instructions)

2 Activities Test. **Answer lines 2a and 2b below.**

		Yes	No
a	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
b	Did the activities described on line 2a, above constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
3	Parent of Supported Organizations. Answer lines 3a and 3b below.		
a	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No", provide details in Part VI.</i>		
b	Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI. the role played by the organization in this regard.</i>		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

- 1** Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in **Part VI**). See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A - Adjusted Net Income

(A) Prior Year

(B) Current Year
(optional)

- | | | | |
|---|----------|--|--|
| 1 Net short-term capital gain | 1 | | |
| 2 Recoveries of prior-year distributions | 2 | | |
| 3 Other gross income (see instructions) | 3 | | |
| 4 Add lines 1 through 3 | 4 | | |
| 5 Depreciation and depletion | 5 | | |
| 6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) | 6 | | |
| 7 Other expenses (see instructions) | 7 | | |
| 8 Adjusted Net Income (subtract lines 5, 6 and 7 from line 4) | 8 | | |

Section B - Minimum Asset Amount

(A) Prior Year

(B) Current Year
(optional)

- | | | | |
|--|-----------|--|--|
| 1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): | 1 | | |
| a Average monthly value of securities | 1a | | |
| b Average monthly cash balances | 1b | | |
| c Fair market value of other non-exempt-use assets | 1c | | |
| d Total (add lines 1a, 1b, and 1c) | 1d | | |
| e Discount claimed for blockage or other factors (explain in detail in Part VI): | | | |
| 2 Acquisition indebtedness applicable to non-exempt use assets | 2 | | |
| 3 Subtract line 2 from line 1d | 3 | | |
| 4 Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions). | 4 | | |
| 5 Net value of non-exempt-use assets (subtract line 4 from line 3) | 5 | | |
| 6 Multiply line 5 by 0.035 | 6 | | |
| 7 Recoveries of prior-year distributions | 7 | | |
| 8 Minimum Asset Amount (add line 7 to line 6) | 8 | | |

Section C - Distributable Amount

Current Year

- | | | |
|---|----------|--|
| 1 Adjusted net income for prior year (from Section A, line 8, Column A) | 1 | |
| 2 Enter 85% of line 1 | 2 | |
| 3 Minimum asset amount for prior year (from Section B, line 8, Column A) | 3 | |
| 4 Enter greater of line 2 or line 3 | 4 | |
| 5 Income tax imposed in prior year | 5 | |
| 6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions) | 6 | |

- 7** Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

(continued)

Section D - Distributions		Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	1	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	3	
4 Amounts paid to acquire exempt-use assets	4	
5 Qualified set-aside amounts (prior IRS approval required - provide details in Part VI)	5	
6 Other distributions (describe in Part VI). See instructions	6	
7 Total annual distributions. Add lines 1 through 6.	7	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions	8	
9 Distributable amount for 2022 from Section C, line 6	9	
10 Line 8 amount divided by Line 9 amount	10	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2022	(iii) Distributable Amount for 2022
1 Distributable amount for 2022 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2022 (reasonable cause required-- explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2022:			
a From 2017.			
b From 2018.			
c From 2019.			
d From 2020.			
e From 2021.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2022 distributable amount			
i Carryover from 2017 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2022 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2022 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2022, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2022. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2023. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2018.			
b Excess from 2019.			
c Excess from 2020.			
d Excess from 2021.			
e Excess from 2022.			

Part VI **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

Return Reference

Explanation

Additional Data

Return to Form

Software ID: 22015461

Software Version: 22.0.1.0

Supplemental Financial Statements

2021

Open to Public Inspection

▶ **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.**

Department of the Treasury
Internal Revenue Service

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 (e.g., recreation or education) Preservation of an historically important land area
 Protection of natural habitat Preservation of a certified historic structure
 Preservation of open space

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 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 in (a)	2c
d Number of conservation easements included in (c) acquired after 7/25/06, 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 2(d) 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 are a significant use of its collection items (check all that apply):
- a** Public exhibition
 - b** Scholarly research
 - c** Preservation for future generations
 - d** Loan or exchange programs
 - e** Other
- 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:
- | | Amount |
|--|-----------|
| c Beginning balance | 1c |
| d Additions during the year | 1d |
| e Distributions during the year | 1e |
| f Ending balance | 1f |
- 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	1,392,526	931,328	833,525	771,591	805,926
b Contributions	55,235	371,493	16,999	11,378	81,947
c Net investment earnings, gains, and losses	-192,833	114,168	96,804	116,556	-50,282
d Grants or scholarships	53,000	15,000	16,000	66,000	66,000
e Other expenditures for facilities and programs	2,000	9,463			
f Administrative expenses					
g End of year balance	1,199,928	1,392,526	931,328	833,525	771,591

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment ▶ 34.000 %
 - b** Permanent endowment ▶ 66.000 %
 - 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:
- | | Yes | No |
|--|-----|----|
| (i) Unrelated organizations | | No |
| (ii) Related organizations | | No |
- b** If "Yes" on 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				
b Buildings				
c Leasehold improvements				
d Equipment		21,003	21,003	
e Other				

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

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		
(2) Closely-held equity interests		
(3) Other _____		
(A) Financial derivatives and other financial products		
(B) Closely-held equity interests		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Column (b) must equal Form 990, Part X, col. (B) line 12.)		

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, col.(B) line 13.)		

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, col.(B) line 15.)	

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.

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

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 FIN 48 (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	380,100
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	-118,797	
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	-118,797
3	Subtract line 2e from line 1		3	498,897
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	
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)		5	498,897

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	557,781
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	
3	Subtract line 2e from line 1		3	557,781
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	
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)		5	557,781

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.

Return Reference	Explanation
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Additional Data

[Return to Form](#)

Software ID: 22015461

Software Version: 22.0.1.0

**SCHEDULE F
(Form 990)**

Statement of Activities Outside the United States

OMB No. 1545-0047

▶ **Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16.**
 ▶ **Attach to Form 990.**
 ▶ **Go to www.irs.gov/Form990 for instructions and the latest information.**

2022

**Open to Public
Inspection**

Department of the Treasury
Internal Revenue Service

Name of the organization
UNITED LEUKODYSTROPHY FOUNDATION INC

Employer identification number
35-1557361

Part I General Information on Activities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

- 1 For grantmakers.** Does the organization maintain records to substantiate the amount of its 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 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- 3** Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Sub-total					
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)		Europe Including Iceland and Greenland	Research	31,940	Wire transfer			
(2)		Europe Including Iceland and Greenland	Research	33,000	Wire transfer			
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								
(10)								
(11)								
(12)								
(13)								
(14)								
(15)								
(16)								

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter

3 Enter total number of other organizations or entities

Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

Part IV Foreign Forms

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* Yes No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)* Yes No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with Respect to Certain Foreign Corporations. (see Instructions for Form 5471)* Yes No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)* . Yes No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* Yes No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990).* Yes No

Additional Data

Software ID: 22015461

Software Version: 22.0.1.0

Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing.

**Schedule I
(Form 990)**

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

OMB No. 1545-0047

2022

**Open to Public
Inspection**

Department of the
Treasury
Internal Revenue Service

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 the latest information.

Name of the organization

UNITED LEUKODYSTROPHY FOUNDATION INC

Employer identification number

35-1557361

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.

(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) Kennedy Krieger Institute 707 N Broadway Baltimore, MD 21205	52-1524967		20,000				Research

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

3 Enter total number of other organizations listed in the line 1 table ▶

1

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.

Return Reference

Explanation

Additional Data

[Return to Form](#)

Software ID: 22015461
Software Version: 22.0.1.0

SCHEDULE O
(Form 990)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 990-EZ.****▶ Go to www.irs.gov/Form990 for the latest information.**

OMB No. 1545-0047

2021**Open to Public
Inspection**Name of the organization
UNITED LEUKODYSTROPHY FOUNDATION INC**Employer identification number**

35-1557361

Return Reference	Explanation
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 organizations 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.

Additional Data

Return to Form

Software ID: 22015461

Software Version: 22.0.1.0