

Return of Organization Exempt From Income Tax**2024**Department of the Treasury
Internal Revenue Service

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

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

Go to www.irs.gov/Form990EZ for instructions and the latest information.**Open to Public
Inspection**

A For the 2024 calendar year, or tax year beginning 07/01/2024 and ending 06/30/2025	
B Check if applicable: ☒ Address change ☐ Name change ☐ Initial return ☐ Final return/terminated ☐ Amended return ☐ Application pending	C Name of organization LYMPHANGIOMATOSIS & GORHAMS DISEASE ALLIANCE INC Number and street (or P.O. box if mail is not delivered to street address) Room/suite 7901 4TH STREET NORTH STE 9153 City or town, state or province, country, and ZIP or foreign postal code SAINT PETERSBURG, FL 33702
D Employer identification number 26-1224181	
E Telephone number 262-227-8453	
F Group Exemption Number	
G Accounting Method: ☒ Cash ☐ Accrual Other (specify): _____	
H Check ☐ if the organization is not required to attach Schedule B (Form 990).	
I Website: www.ldgalliance.org	
J Tax-exempt status (check only one) — ☒ 501(c)(3) ☐ 501(c) () (insert no.) ☐ 4947(a)(1) or ☐ 527	
K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other: _____	
L Add lines 5b, 6c, and 7b to line 9 to determine gross receipts. If gross receipts are \$200,000 or more, or if total assets (Part II, column (B)) are \$500,000 or more, file Form 990 instead of Form 990-EZ \$ 118,890	

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (see the instructions for Part I)			
Check if the organization used Schedule O to respond to any question in this Part I ☒			
Revenue	1	Contributions, gifts, grants, and similar amounts received	113,613
	2	Program service revenue including government fees and contracts	0
	3	Membership dues and assessments	0
	4	Investment income	5,277
	5a	Gross amount from sale of assets other than inventory	0
	5b	Less: cost or other basis and sales expenses	0
	5c	Gain or (loss) from sale of assets other than inventory (subtract line 5b from line 5a)	0
	6	Gaming and fundraising events:	
	6a	Gross income from gaming (attach Schedule G if greater than \$15,000)	0
	6b	Gross income from fundraising events (not including \$ 0 of contributions from fundraising events reported on line 1) (attach Schedule G if the sum of such gross income and contributions exceeds \$15,000)	0
6c	Less: direct expenses from gaming and fundraising events	0	
6d	Net income or (loss) from gaming and fundraising events (add lines 6a and 6b and subtract line 6c)	0	
Revenue	7a	Gross sales of inventory, less returns and allowances	0
	7b	Less: cost of goods sold	0
	7c	Gross profit or (loss) from sales of inventory (subtract line 7b from line 7a)	0
	8	Other revenue (describe in Schedule O)	0
	9	Total revenue. Add lines 1, 2, 3, 4, 5c, 6d, 7c, and 8	118,890
Expenses	10	Grants and similar amounts paid (list in Schedule O)	26,090
	11	Benefits paid to or for members	0
	12	Salaries, other compensation, and employee benefits	0
	13	Professional fees and other payments to independent contractors	109,604
	14	Occupancy, rent, utilities, and maintenance	0
	15	Printing, publications, postage, and shipping	2,079
	16	Other expenses (describe in Schedule O) <u>See Schedule O, Statement 1</u>	15,327
	17	Total expenses. Add lines 10 through 16	153,100
Net Assets	18	Excess or (deficit) for the year (subtract line 17 from line 9)	-34,210
	19	Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with end-of-year figure reported on prior year's return)	378,745
	20	Other changes in net assets or fund balances (explain in Schedule O)	11
	21	Net assets or fund balances at end of year. Combine lines 18 through 20	344,546

Part II Balance Sheets (see the instructions for Part II)Check if the organization used Schedule O to respond to any question in this Part II ☒

	(A) Beginning of year		(B) End of year
22 Cash, savings, and investments	271,060	22	233,757
23 Land and buildings	0	23	0
24 Other assets (describe in Schedule O) <u>See Schedule O, Statement 2.</u>	115,193	24	120,068
25 Total assets	386,253	25	353,825
26 Total liabilities (describe in Schedule O) <u>See Schedule O, Statement 3.</u>	7,508	26	9,279
27 Net assets or fund balances (line 27 of column (B) must agree with line 21)	378,745	27	344,546

Part III Statement of Program Service Accomplishments (see the instructions for Part III)Check if the organization used Schedule O to respond to any question in this Part III ☐What is the organization's primary exempt purpose? See Schedule O, Statement 4

Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. In a clear and concise manner, describe the services provided, the number of persons benefited, and other relevant information for each program title.

Expenses
(Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)

28 <u>OUR PATIENT SUPPORT SERVICES INCLUDED THE MANAGEMENT OF OUR PATIENT REGISTRY TO SUPPORT RESEARCH NEEDS, TRACK VITAL INFORMATION ABOUT CLAS, AND ANSWER</u> (Continued on Schedule O, Statement 5) (Grants \$ <u>0</u>) If this amount includes foreign grants, check here ☐	28a	44,000
29 <u>OUR OUTREACH PROGRAM INCREASES AWARENESS OF THE CLAS THROUGH OUR WEBSITE, SOCIAL MEDIA, AND EVENTS SUCH AS CLA AWARENESS DAY AND RARE DISEASE DAY.</u> (Continued on Schedule O, Statement 6) (Grants \$ <u>0</u>) If this amount includes foreign grants, check here ☐	29a	37,369
30 <u>RESEARCH - IN THIS AREA, WE HOST A CLA WEBINAR SERIES FOR RESEARCH. PRESENTATIONS ARE POSTED ONLINE FOR THE GENERAL PUBLIC. RAISED FUNDS FOR RESEARCH GRANTS</u> (Continued on Schedule O, Statement 7) (Grants \$ <u>26,090</u>) If this amount includes foreign grants, check here ☐	30a	31,046
31 Other program services (describe in Schedule O) (Grants \$ <u>0</u>) If this amount includes foreign grants, check here ☐	31a	0
32 Total program service expenses (add lines 28a through 31a)	32	112,415

Part IV List of Officers, Directors, Trustees, and Key Employees (list each one even if not compensated—see the instructions for Part IV)Check if the organization used Schedule O to respond to any question in this Part IV ☐

(a) Name and title	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC/1099-NEC) (if not paid, enter -0-)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
LOUISE MURGIA DIRECTOR OF OPERATIONS	40.00	64,608	0	0
MICHAEL KELLY EXECUTIVE DIRECTOR	20.00	3,125	0	0
SCOTT WEISNER PRESIDENT	2.00	0	0	0
SCOTT GOLDFARB TREASURER	2.00	0	0	0
TIFFANY FERRY BOARD MEMBER	2.00	0	0	0
MITCH MAERSCH BOARD MEMBER	2.00	0	0	0
SEAN CHASTAIN BOARD MEMBER	2.00	0	0	0
KEVIN MARTIN BOARD MEMBER	2.00	0	0	0
SAMIRA FAROUNI BOARD MEMBER	2.00	0	0	0
OFELIA RODRIGUEZ NIEVAS BOARD MEMBER	2.00	0	0	0

Part V Other Information (Note the Schedule A and personal benefit contract statement requirements in the instructions for Part V.) Check if the organization used Schedule O to respond to any question in this Part V ☐

	Yes	No
33 Did the organization engage in any significant activity not previously reported to the IRS? If "Yes," provide a detailed description of each activity in Schedule O		☒
34 Were any significant changes made to the organizing or governing documents? If "Yes," attach a conformed copy of the amended documents if they reflect a change to the organization's name. Otherwise, explain the change on Schedule O. See instructions		☒
35a Did the organization have unrelated business gross income of \$1,000 or more during the year from business activities (such as those reported on lines 2, 6a, and 7a, among others)?		☒
b If "Yes" to line 35a, has the organization filed a Form 990-T for the year? If "No," provide an explanation in Schedule O		
c Was the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization subject to section 6033(e) notice, reporting, and proxy tax requirements during the year? If "Yes," complete Schedule C, Part III		☒
36 Did the organization undergo a liquidation, dissolution, termination, or significant disposition of net assets during the year? If "Yes," complete applicable parts of Schedule N		☒
37a Enter amount of political expenditures, direct or indirect, as described in the instructions 37a 0		
b Did the organization file Form 1120-POL for this year?		☒
38a Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee; or were any such loans made in a prior year and still outstanding at the end of the tax year covered by this return?		☒
b If "Yes," complete Schedule L, Part II, and enter the total amount involved 38b		
39 Section 501(c)(7) organizations. Enter:		
a Initiation fees and capital contributions included on line 9 39a		
b Gross receipts, included on line 9, for public use of club facilities 39b		
40a Section 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under:		
section 4911: 0; section 4912: 0; section 4955: 0		
b Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year, or did it engage in an excess benefit transaction in a prior year that has not been reported on any of its prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I		☒
c Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958 0		
d Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax on line 40c reimbursed by the organization 0		
e All organizations. At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If "Yes," complete Form 8886-T		☒
41 List the states with which a copy of this return is filed: FL		
42a The organization's books are in care of: MICHAEL KELLY Telephone no. 262-227-8453		
Located at: 7901 4TH ST N STE 9153, ST PETERSBURG, FL 33702 ZIP + 4 33702		
b 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)?	Yes	No
If "Yes," enter the name of the foreign country:		☒
See the instructions for exceptions and filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
c At any time during the calendar year, did the organization maintain an office outside the United States?		☒
If "Yes," enter the name of the foreign country:		
43 Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of Form 1041 —Check here ☐ and enter the amount of tax-exempt interest received or accrued during the tax year 43		
44a Did the organization maintain any donor advised funds during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ		☒
b Did the organization operate one or more hospital facilities during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ		☒
c Did the organization receive any payments for indoor tanning services during the year?		☒
d If "Yes" to line 44c, has the organization filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O		
45a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		☒
b Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," Form 990 and Schedule R may need to be completed instead of Form 990-EZ. See instructions		☒

46 Did the organization engage, directly or indirectly, in political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I

	Yes	No
46		☒

Part VI Section 501(c)(3) Organizations Only

All section 501(c)(3) organizations must answer questions 47–49b and 52, and complete the tables for lines 50 and 51.

Check if the organization used Schedule O to respond to any question in this Part VI ☐

47 Did the organization engage in lobbying activities or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II

	Yes	No
47		☒

48 Is the organization a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E

48		☒
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49a Did the organization make any transfers to an exempt non-charitable related organization?

49a		☒
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b If "Yes," was the related organization a section 527 organization?

49b		
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50 Complete this table for the organization's five highest compensated employees (other than officers, directors, trustees, and key employees) who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and title of each employee	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC/1099-NEC)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
None				

f Total number of other employees paid over \$100,000

51 Complete this table for the organization's five highest compensated independent contractors who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and business address of each independent contractor	(b) Type of service	(c) Compensation
None		

d Total number of other independent contractors each receiving over \$100,000

52 Did the organization complete Schedule A? **Note:** All section 501(c)(3) organizations must attach a completed Schedule A ☒ **Yes** ☐ **No**

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 <i>michael kelly</i>		Date 10/28/2025		
	Type or print name and title MICHAEL KELLY, EXECUTIVE DIRECTOR				
Paid Preparer Use Only	Print/Type preparer's name JEREMY CORK	Preparer's signature <i>jeremy cork</i>	Date 10/28/2025	Check ☐ if self-employed	PTIN P01544850
	Firm's name EASY OFFICE DBA JITASA			Firm's EIN 26-2176601	
	Firm's address 1120 S RACKHAM WAY SUITE 300, MERIDIAN, ID 83642			Phone no. 208-287-4777	

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

SCHEDULE A
(Form 990)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2024

Open to Public
Inspection

Name of the organization

LYMPHANGIOMATOSIS & GORHAMS DISEASE ALLIANCE INC

Employer identification number

26-1224181

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)(vii)**. (Complete Part II.)
- 9 ☐ An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: _____
- 10 ☒ An organization that normally receives (1) more than 33¹/₃% 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 33¹/₃% 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		
(A)						
(B)						
(C)						
(D)						
(E)						
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 fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
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						
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)						
6 Public support. Subtract line 5 from line 4						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
7 Amounts from line 4						
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
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						
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 2024 (line 6, column (f), divided by line 11, column (f))	14	%
15 Public support percentage from 2023 Schedule A, Part II, line 14	15	%
16a 33¹/₃% support test—2024. 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 33¹/₃% support test—2023. 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—2024. 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—2023. 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

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	224,895	320,875	118,418	251,887	113,613	1,029,688
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose				13,500		13,500
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5	224,895	320,875	118,418	265,387	113,613	1,043,188
7a Amounts included on lines 1, 2, and 3 received from disqualified persons . .			35,462	21,026	15,000	71,488
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b	0	0	35,462	21,026	15,000	71,488
8 Public support. (Subtract line 7c from line 6.)						971,700

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
9 Amounts from line 6	224,895	320,875	118,418	265,387	113,613	1,043,188
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	131	843	2,845	5,155	5,277	14,251
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b	131	843	2,845	5,155	5,277	14,251
11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)	225,026	321,718	121,263	270,542	118,890	1,057,439
14 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

15 Public support percentage for 2024 (line 8, column (f), divided by line 13, column (f))	15	91.89 %
16 Public support percentage from 2023 Schedule A, Part III, line 15	16	95.55 %

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2024 (line 10c, column (f), divided by line 13, column (f))	17	1.35 %
18 Investment income percentage from 2023 Schedule A, Part III, line 17	18	1.1 %
19a 33¹/₃% support tests—2024. 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 . The organization qualifies as a publicly supported organization	☒	
b 33¹/₃% support tests—2023. 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 . The organization qualifies as a publicly supported organization	☐	
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, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, 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? <i>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.</i>		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i>		
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)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i>		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>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.</i>		
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)? <i>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.</i>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>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).</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as 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? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
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))? <i>If "Yes," provide detail in Part VI.</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
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)? <i>If "Yes," answer line 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

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?		
11a		
b A family member of a person described on line 11a above?		
11b		
c A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI .		
11c		

Section B. Type I Supporting Organizations

	Yes	No
1 Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? 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 officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.		
1		
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? 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.		
2		

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)? 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).		
1		

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?		
1		
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? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).		
2		
3 By reason of the relationship described on 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? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.		
3		

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 governmental entity (see instructions).			
2 Activities Test. Answer lines 2a and 2b below.			
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? 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.			
2a			
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? 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.			
2b			
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? If "Yes" or "No," provide details in Part VI .			
3a			
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.			
3b			

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):		
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 (<i>explain in detail in Part VI</i>):		
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 0.85 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 2024 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-2024	(iii) Distributable Amount for 2024
1 Distributable amount for 2024 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2024 (reasonable cause required—explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2024			
a From 2019			
b From 2020			
c From 2021			
d From 2022			
e From 2023			
f Total of lines 3a through 3e			
g Applied to underdistributions of prior years			
h Applied to 2024 distributable amount			
i Carryover from 2019 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2024 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2024 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2025. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2020 . . .			
b Excess from 2021 . . .			
c Excess from 2022 . . .			
d Excess from 2023 . . .			
e Excess from 2024 . . .			

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.)

Other Expenses Structured Explanation

Description	Amount
OFFICE EXPENSES	10,725
INSURANCE EXPENSES	2,935
ADVERTISING EXPENSES	1,595
INTEREST EXPENSES	72
Total:	15,327

Other Assets Structured Explanation

Description	EOY Amount
INVESTMENTS PUBLICLY TRADED SECURITIES	119,435
PREPAID EXPENSES	633
Total:	120,068

Other Liabilities Structured Explanation

Description	EOY Amount
ACCOUNTS PAYABLE	9,279
Total:	9,279

Primary Exempt Purpose

Primary Exempt Purpose

WORLDWIDE PATIENT SUPPORT PROGRAM WHICH INCLUDES A PATIENT REGISTRY, A WEBSITE WITH RARE DISEASE INFORMATION AND PATIENT DISCUSSION FORUM.

First Program Service Accomplishments Description

Description

QUESTIONS ABOUT THE DISEASES. THE PROGRAMS ALSO SUPPORTS THE MANAGEMENT OF SEVERAL ONLINE SUPPORT GROUPS.

Second Program Service Accomplishments Description

Description

PARTNERSHIPS WITH OTHER RARE DISEASE ORGANIZATIONS AND FOUNDATIONS. ALSO, COVERS WORK FOR NEWSLETTER AND WORK WITH ADVISORY COUNCILS.

Third Program Service Accomplishments Description

Description

SPECIFIC TO CLAS. ALSO, LAY SUMMARIES ARE CREATED TO EDUCATE THE PUBLIC ABOUT NEW RESEARCH PAPERS AND DISCOVERIES. THIS AREA ALSO COVERS WORK WITH OUR MEDICAL AND SCIENTIFIC ADVISORY COUNCIL.