## **Return of Organization Exempt From Income Tax**

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

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

▶ 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.

Open to Public Inspection

Α	For the	e 2020 calen	dar year, or tax year beginning Jul. 1, 2020, an	nd ending	Ju	n 30	, <b>20</b> 21							
В	Check i	f applicable:	C Name of organization Lymphangiomatosis & Gorham's Disea	se Allia	nce, Inc.	D Employe	er identification number							
	Address	s change	Doing business as			26-122								
	Name c	hange	Number and street (or P.O. box if mail is not delivered to street address)	Roor		E Telephor	·····							
	Initial re	turn	7901 4 St N Ste 5761			· ·	27-8453							
	Final ret	urn/terminated	City or town, state or province, country, and ZIP or foreign postal code			, , , , , , ,								
	Amende	ed return	Saint Petersburg, FL 33702			<b>G</b> Gross re	ceipts\$ 323,008.							
	Applicat	tion pending	F Name and address of principal officer:				ubordinates? Yes X No							
			Mark Kelly MD PHD, 19919 Villa Lante Place, Boca Raton,	FL 33434										
1	Tax-exe	mpt status:	X 501(c)(3)	527			See instructions							
J	Website	e: ► www.l	dgallaince.org	7	H(c) Group ex									
K				r of formation			legal domicile: FL							
Р	art I	Summai		***************************************		σιαισ σι	rogal doffiloso: I II							
	1	Briefly des	cribe the organization's mission or most significant activities:	Worldwide nati	ent support prog	ram which in	aludae a nationt maintru							
Ö		Briefly describe the organization's mission or most significant activities: Norldwide patient support program which includes a patient registry, a website with rare disease information & patient discussion forum.												
Activities & Governance		w measure with larg disease information & patient discussion forum.												
ē	2	Check this	box ► ☐ if the organization discontinued its operations or dis	sposed of	more than 2	5% of its	net accete							
é	3	Number of	voting members of the governing body (Part VI, line 1a)	opocoa or	more than 2	3	5 1101 433013.							
ಷ	4	Number of	independent voting members of the governing body (Part VI,	line 1h)		4	5							
ies	5	Total numb	per of individuals employed in calendar year 2020 (Part V, line	2a)	• • • •	5								
Ξ	6	Total numb	per of volunteers (estimate if necessary)	<i>–</i> a)		6	0 5							
Ą	7a	Total unrela	ated business revenue from Part VIII, column (C), line 12		• • • •	7a								
	b	Net unrelat	ted business taxable income from Form 990-T, Part I, line 11	·. · · ·		7b	1,749.							
			The state of the s	· · · · ·	Prior Year	10	0. Current Year							
ď.	8	Contributio		7.20										
Revenue	9	Program se	ons and grants (Part VIII, line 1h)	315,	138.	321,259.								
š	10		t income (Part VIII, column (A), lines 3, 4, and 7d)		21.6									
æ	11	Other rever	nue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	4,	316.	1,749.								
	12	Total revenu	200	25.										
	13	Grants and	ue – add lines 8 through 11 (must equal Part VIII, column (A), lin I similar amounts paid (Part IX, column (A), lines 1-3)	e 12)	320,0		323,008.							
	14	Renefits na	11,	330.	37,000.									
m	15		aid to or for members (Part IX, column (A), line 4) her compensation, employee benefits (Part IX, column (A), lines 5											
Expenses		Professions	at fundraising foos (Part IV, column (A), line 11a)		142.	201.								
nec	b	Total fundr	airing expanses (Part IX, column (D), line 35)	sing fees (Part IX, column (A), line 11e)										
ă	17	Other expe	space (Dort IV and some /A) Brand 44 and 44 and 5	01.		577.	174,189.							
			nses, Add lines 13–17 (must equal Part IX, column (A), line 25)											
			iss expenses. Subtract line 18 from line 12		106,0		211,390.							
노였		ricveride ie.	SS expenses. Subtract line 18 from line 12		214,0		111,618.							
Net Assets or Fund Balances	20	Total accet	s (Part X, line 16)	Beg	inning of Curre		End of Year							
Ass			ties (Part X, line 16)	· ·	552,9		662,607.							
E et			or fund balances. Subtract line 21 from line 20	• •		144.	5,530.							
Da	rt II	Signatur		• •	545,4	159.	657,077.							
		·····												
true	, correct,	, and complete	declare that I have examined this return, including accompanying schedules and Declaration of preparer (other than officer) is based on all information of which	and statemer h breparer ha	nts, and to the t s any knowledg	pest of my l	knowledge and belief, it is							
				- F F										
Sig	n	Signatur	re of officer		04/202	21								
He					Date									
110			nael Kelly MD PHD, President print name and title											
	i	L./ <sub>1</sub>												
Pai		Davil D	preparer's name Preparer's signature	Date			if PTIN							
	pare	<b></b>	ubin Phd EA Mtax	11/			P00315971							
Us	e Only	Firm's name	THE THE TAX TO SEE THE TAX THE		Firm's E	EIN ► 03	-0481340							
		Firm's addr	ress ► 2080 NW BOCA RATON BLVD, SUITE 6, BOCA RATO	ON, FL 3	3431 Phone r	no. (561	)750-8299							
ıvıay	the IR	o aiscuss th	his return with the preparer shown above? See instructions		<u> </u>		X Yes ☐ No							

Part	
1	Check if Schedule O contains a response or note to any line in this Part III
•	Worldwide patient support program which includes a patient registry,
	a website with rare disease information & patient discussion forum.
2	Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?
3	If "Yes," describe these new services on Schedule O.  Did the organization cease conducting, or make significant changes in how it conducts, any program
	services?
4	Describe the organization's program service accomplishments for each of its three largest program services, as measured be 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 \$ 163,543. including grants of \$ 0.) (Revenue \$ 0.)
	Worldwide patient support program which includes a patient registry,
	a website with rare disease information & patient discussion forum.
4b	(Code:) (Expenses \$ 27,000. including grants of \$ 0.) (Revenue \$ 0.)  Research Grant to University of PA
4c	(Code: )(Expenses\$ 10,000.including grants of\$ 0.)(Revenue\$ 0.)  Grant to Uplift Athlete - a pilot program.
4d	Other program services (Describe on Schedule O.)  Expenses \$ including grants of \$ ) (Revenue \$ )
40	Total program service expenses > 200 542

Part	IV Checklist of Required Schedules			<u>-</u>
			Yes	No
1	is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	1	×	
2	Is the organization required to complete Schedule B, Schedule of Contributors See instructions?	2	×	·
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3		×
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? If "Yes," complete Schedule C, Part II	4		×
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 Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III	5		×
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? If "Yes," complete Schedule D, Part I	6		×
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7		×
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8		×
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? If "Yes," complete Schedule D, Part IV	9		×
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? If "Yes," complete Schedule D, Part V	10		×
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, IX, or X as applicable.			70 / E.
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI	11a		×
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? If "Yes," complete Schedule D, Part VII	11b		×
С	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? If "Yes," complete Schedule D, Part VIII	11c		×
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? If "Yes," complete Schedule D, Part IX	11d	×	
e	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	×	
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)? If "Yes," complete Schedule D, Part X	11f		×
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	12a		×
b	Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b		×
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13		×
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		×
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? If "Yes," complete Schedule F, Parts I and IV.	4.4		
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? If "Yes," complete Schedule F, Parts II and IV	14b		×
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? If "Yes," complete Schedule F, Parts III and IV.			×
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? If "Yes," complete Schedule G, Part I See instructions	16	×	
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II.	18		X
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a?  If "Yes," complete Schedule G, Part III	19		×
20a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		·×
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		
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? If "Yes," complete Schedule I, Parts I and II	21	×	

Part	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? If "Yes," complete Schedule I, Parts I and III	22		×
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? If "Yes," complete Schedule J	23		×
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? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a	24a		×
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
С	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?			
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? If "Yes," complete Schedule L, Part I	25a		×
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? If "Yes," complete Schedule L., Part I	25b		×
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? If "Yes," complete Schedule L, Part II	26		×
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? If "Yes," complete Schedule L, Part III	27		×
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions, for applicable filing thresholds, conditions, and exceptions):			
	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If "Yes," complete Schedule L, Part IV	28a		×
þ	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b		×
C	A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If "Yes," complete Schedule L, Part IV	28c		×
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29		×
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M	30		×
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		×
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II	32		×
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? If "Yes," complete Schedule R, Part I	33		×
	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1	34		×
	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		×
	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)? If "Yes," complete Schedule R, Part V, line 2	35b		
	<b>Section 501(c)(3) organizations.</b> Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2	36		×
	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? If "Yes," complete Schedule R, Part VI	37		×
	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? <b>Note:</b> All Form 990 filers are required to complete Schedule O.	38	×	
Part \	Statements Regarding Other IRS Filings and Tax Compliance Check if Schedule O contains a response or note to any line in this Part V		· · · · ·	
	Followith a number was study in Page 0 of Fig. 4200 ff to 10 of Fig. 10 of Fi		Yes	No
b	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable 1a 0  Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable 1b 0			
c	Did the organization comply with backup withholding rules for reportable payments to vendors and		nicznia:	

Part	V Statements Regarding Other IRS Filings and Tax Compliance (continued)		~~~		<del>-</del>
				Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax			W	
	Statements, filed for the calendar year ending with or within the year covered by this return	2a	0		
b	If at least one is reported on line 2a, did the organization file all required federal employment	tax returns? .	2b		×
	Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see inst	ructions)			(A. )/
За	Did the organization have unrelated business gross income of \$1,000 or more during the year		3a		×
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on S		3b		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other	er authority over,			
	a financial account in a foreign country (such as a bank account, securities account, or other financial	cial account)?	4a		×
b	If "Yes," enter the name of the foreign country ▶		ů.		2 10 10 10 10 10 10 10 10 10 10 10 10 10
	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial			VQ.48	10
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax		5a		×
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter	r transaction?	5b		×
С	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		5c		
6a	Does the organization have annual gross receipts that are normally greater than \$100,0 organization solicit any contributions that were not tax deductible as charitable contributions:		6a		×
b	If "Yes," did the organization include with every solicitation an express statement that such gifts were not tax deductible?	contributions or	6b		
7	Organizations that may receive deductible contributions under section 170(c).		<b>2</b> 2.75 (1)		6) (XX)
а	Did the organization receive a payment in excess of \$75 made partly as a contribution and	partly for goods			
	and services provided to the payor?		7a		×
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		7b		
C	Did the organization sell, exchange, or otherwise dispose of tangible personal property t	or which it was			
	required to file Form 8282?	,	7с		×
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d			
е	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal be		7е		×
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal bene		7f		×
9	If the organization received a contribution of qualified intellectual property, did the organization file Form				
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization fi				
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund m	aintained by the		1000	
	sponsoring organization have excess business holdings at any time during the year?		8	Majorda esta	6987-000000
9	Sponsoring organizations maintaining donor advised funds.				
a	Did the sponsoring organization make any taxable distributions under section 4966?		9a		
b 10	Did the sponsoring organization make a distribution to a donor, donor advisor, or related pers	son?	9b	**************************************	PROTOGRA
10	Section 501(c)(7) organizations. Enter:	اما			
a b	Initiation fees and capital contributions included on Part VIII, line 12	10a	_		
11	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities . Section 501(c)(12) organizations. Enter:	10b	- 346		
''a	Gross income from members or shareholders	11a			
	Gross income from other sources (Do not net amounts due or paid to other sources	IIa	_		· ·
u	against amounts due or received from them.)	11b	i ava	in the second	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu		12a	A 5078153	
	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b		1000	74. MV
13	Section 501(c)(29) qualified nonprofit health insurance issuers.				
а	Is the organization licensed to issue qualified health plans in more than one state?		13a	41.185A 19115	- 11-31103
	Note: See the instructions for additional information the organization must report on Schedul	e O.		17.5	
b	Enter the amount of reserves the organization is required to maintain by the states in which				
	the organization is licensed to issue qualified health plans	13b			
C	Enter the amount of reserves on hand	13c			
14a	Did the organization receive any payments for indoor tanning services during the tax year? .		14a		×
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on	Schedule O .	14b		
	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in				
	excess parachute payment(s) during the year?		15		
	If "Yes," see instructions and file Form 4720, Schedule N.				
16	Is the organization an educational institution subject to the section 4968 excise tax on net inve	stment income?	16		
	If "Yes," complete Form 4720, Schedule O.				

Part	Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O.	r, and See in	for a struc	"No" tions.
	Check if Schedule O contains a response or note to any line in this Part VI			<u> </u>
Secti	ion A. Governing Body and Management			·
			Yes	No
1a		2		
	If there are material differences in voting rights among members of the governing body, or			
	if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.			
h		(X) (A)		
b	Enter the number of voting members included on line 1a, above, who are independent .   1b 5	4		
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	2		×
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person? .	3		×
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		×
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5		×
6	Did the organization have members or stockholders?	6		×
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?	7a	×	
b	Are any governance decisions of the organization reserved to (or subject to approval by) members,	1		
~	stockholders, or persons other than the governing body?	7b	ļ	×
8	Did the organization contemporaneously document the meetings held or written actions undertaken during			
_	the year by the following:			
а	The governing body?	8a	X	
b	Each committee with authority to act on behalf of the governing body?	8b		×
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O	9		×
Secti	ion B. Policies (This Section B requests information about policies not required by the Internal Rever	- ;	ode.)	
			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a		×
b	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?	10b		
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a		×
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.			X,*\*Y.*
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	×	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	×	
C	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	12c	×	
13	Did the organization have a written whistleblower policy?	13	×	
14	Did the organization have a written document retention and destruction policy?	14	×	
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?			
а	The organization's CEO, Executive Director, or top management official	15a		×
b	Other officers or key employees of the organization	15b		×
	If "Yes" to line 15a or 15b, describe the process in 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?	16a		×
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its			AV TO
	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?	16b		
Secti	on C. Disclosure	1.00		L
17	List the states with which a copy of this Form 990 is required to be filed.			
18	Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-			501(c)
	(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.  Own website  Another's website  Upon request  Other (explain on Schedule O)	1 (000	uon i	) (C)
19	Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of and financial statements available to the public during the tax year.	of inter	est p	olicy,
20	State the name, address, and telephone number of the person who possesses the organization's books and re	ecords	<b>&gt;</b>	

# 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 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 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See instructions for the order in which to list the persons above.

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

					C)					
(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	office or direct	unles er an	neck ss pe	rson	than of the state	an	(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
(1) Michael Kelly MD PHD	30.00			ļ <u></u>		8.				
Executive Director	1	×		×						
(2) Scott Weisner	10.00			<b></b>	ļ					
Chairman	1	×		×						
(3) Scott Goldfarb	5.00									
Director		×								
(4) Tiffany Ferry	30.00									
Director		×								
(5) Mitch Maersch	5.00									
Director		×			<u> </u>					
(6)										
(7)										
			ļ			******				
(8)										
(9)	***************************************									
(10)										
(11)										
			_							
(12)										
(13)					-					
(14)										

Part	VII Section A. Officers, Directors,	Trustees,	Key I	Emį	plo	yee	s, an	d F	lighest Compe	nsated	Emplo	yees (continued)
						C)						
	(A)	(B)	(do n	ot et		ition	e than d	nna	(D)	(E)		(F)
	Name and title	Average	3 '				is both		an Reportable Repo			Estimated amount
		hours per week	office	er and	dad	lirect	or/trus	from the from r			sation of other	į.
		(list any	or ind	고	Officer	6	용품	ਹੁ	organization	organiza		compensation from the
		hours for	ìvid	臣	icer	g	pio	Former	(W-2/1099-MISC)	(W-2/1099		organization and
		related organizations	Individual trustee or director	Institutional trustee		Key employee	Highest compensated employee					related organizations
		below	, trus	함		) yee	ğ					
		dotted line)	tee	uste		"	ens					
				8			ated					
(15)	3					╁		<del> </del>		6		
1.0)		· · · · · · · · · · · · · · · · · · ·	,									
/1 C)												<u> </u>
(16)												
(4-)						<del> </del>						
(17)												
						ļ		ļ				
(18)												
(19)												
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(20)												
3===2			1									
(21)				-		<del> </del>		<del> </del>				
1211			1									:
(00)						<u> </u>		ļ				
(22)												
						<u> </u>						
(23)												
(24)												
(25)												
J	*	<b></b>	-									
1b	Subtotal	1	J	L	J	<u></u>	l					
c	Total from continuation sheets to Part		n A	•	•							
ď		•		•	•	•						
								<u>.</u>				
2	Total number of individuals (including bu		to tr	ose	lis1	tea	apove	e) w	no received mor	e than \$1	00,000	of
	reportable compensation from the organ	ization >										
												Yes No
3	Did the organization list any former	officer, dire	ector,	tru	ste	e, k	кеу е	mpl	loyee, or highes	st compe	ensated	
	employee on line 1a? If "Yes," complete	Schedule J	for su	ıch	ind	ivid	ual					3 ×
4	For any individual listed on line 1a, is the	sum of re	portal	ole -	con	npe	nsatio	n a	nd other compe	nsation fr	om the	
-	organization and related organizations											
	individual	g. 54.15.						_,		34.0 0 70	,, ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	4 ×
-			. ,		, L:	· .	. ,			 	ere. Martinian	A SIGNA CANNON ASSET A HISSON ON BURGOT AND OUT OF A PROPERTY OF
5	Did any person listed on line 1a receive of for services rendered to the organization											3
Cooti	on B. Independent Contractors	: 11 163, 0	Jonnpi	ere	361	ieui	110 0 1	OI S	sucriperson .			5 X
1	Complete this table for your five high											
	compensation from the organization. Rep	ort compen	sation	1 for	the	e ca	lenda	r ye	ar ending with or	within th	e orgar	nization's tax year.
	(A)								(B)			(C)
	Name and business add	fress							Description of sen	vices		Compensation
								-				
								-				
							··· · · ·	-				
2	Total number of independent contractor							o th	lose listed abov	re) who		
	received more than \$100,000 of compens	ation from	the or	gan	izat	ion	<b>&gt;</b>					

Par	t VIII	Statement of Re Check if Schedule			espor	ise or note to a	ny line in this Pa	urt VIII		
		Onosicii Gonogaio		Titalii o a i i	<u> </u>	NO 01 11010 10 10	(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 b c d e f	Federated campaig Membership dues Fundraising events Related organizatio Government grants All other contribution and similar amounts no	 ns . (cont	ributions)	1a 1b 1c 1d 1e	321,259.				
Contrib and Oth		Noncash contribution lines 1a-1f			1g		321,259.			
Program Service Revenue	2a b c d e f	All other program so	ervice	revenue		Business Code				
	3 4 5	Total. Add lines 2a- Investment income other similar amour Income from investr Royalties	incl nts) . nent o	uding divi  of tax-exen	dends  npt bo	s, interest, and ▶ and proceeds ▶ ▶	1,749.	0.	1,749.	0 -
	6a b c d	Gross rents Less: rental expenses Rental income or (loss) Net rental income of Gross amount from sales of assets	6c	(i) Rea		(ii) Personal				
Other Revenue	b c d 8a	other than inventory Less: cost or other basis and sales expenses Gain or (loss) Net gain or (loss) Gross income fro	 m fu							
Ď	b c 9a	events (not including of contributions re 1c). See Part IV, line Less: direct expens Net income or (loss Gross income of activities. See Part I	portede 18 es . ) from from V, line	  fundraisir gaming a 19 .	9a	nts ▶				
		Less: direct expens Net income or (loss) Gross sales of ir returns and allowan Less: cost of goods Net income or (loss)	) from evento ces sold	gaming a pry, less	10a 10b					
Miscellaneous Revenue	11a b c d					Business Code				
	12	Total revenue. See					323,008.	0.	1,749.	0.

	IX Statement of Functional Expenses				
Section	on 501(c)(3) and 501(c)(4) organizations must comp			must complete colur	nn (A).
	Check if Schedule O contains a response	e or note to any line	e in this Part IX .		🗌
	ot include amounts reported on lines 6b, 7b, b, and 10b of Part VIII.	(A) Total expenses	<b>(B)</b> Program service expenses	(C) Management and general expenses	<b>(D)</b> Fundraising expenses
1	Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	37,000.	37,000.		
2	Grants and other assistance to domestic individuals. See Part IV, line 22		3,7000,		
3	Grants and other assistance to foreign				
*	organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	٠, ١٩	1		
4 5	Benefits paid to or for members Compensation of current officers, directors, trustees, and key employees				
6	Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7	Other salaries and wages				
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9	Other employee benefits				
10	Payroll taxes				
11	Fees for services (nonemployees):			<u></u> .	
a	Management				
b	Legal	873.	0.	873.	0
C	Accounting	2,000.	0.		0.
_		2,000.	U.	2,000.	0.
d	Lobbying				
e	Professional fundraising services. See Part IV, line 17	201.			201.
f	Investment management fees				
g	Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.)				
12	Advertising and promotion				
13	Office expenses	682.	0.	682.	0.
14	Information technology				
15	Royalties				
16	Occupancy				
17	Travel				
18	Payments of travel or entertainment expenses				
10	for any federal, state, or local public officials				
40	•	01 450	0.1		
19	Conferences, conventions, and meetings .	21,479.	21,479.	0.	0.
20	Interest				
21	Payments to affiliates				
22	Depreciation, depletion, and amortization .				
23	Insurance	1,988.	0.	1,988.	0.
24	Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If				
	line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)	909 (1865) 19 (1861) 146 (188 2009 (1866) 18 (1866) 18 (1866)			
a	Patient Registry	65,115.	65,115.	0.	0.
b	Research	76,949.	76,949.	0.	0.
С	Business Annual Fees	114.	0.	114.	0.
đ					
е	All other expenses	4,989.	0.	4,989.	0.
25	Total functional expenses. Add lines 1 through 24e	211,390.	200,543.	10,646.	201.
26	Joint costs. Complete this line only if the		200,010.		~ J.
	organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ▶ ☐ if				

25

26

Net Assets or Fund Balances

Form 990 (2020) Page 11 Part X Balance Sheet Check if Schedule O contains a response or note to any line in this Part X Beginning of year End of year Cash - non-interest-bearing 1 424,645. 532,740. 1 2 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 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 7 8 Prepaid expenses and deferred charges . . . 9 9 10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D . . . 10a Less: accumulated depreciation . . . . . 10b 10c 11 Investments—publicly traded securities . . . . . 11 12 Investments—other securities. See Part IV, line 11. 12 13 Investments—program-related. See Part IV, line 11. 13 14 14 15 128,258. 129,867. 15 16 Total assets. Add lines 1 through 15 (must equal line 33) . . . . . 662,607. 552,903. 16 17 17 18 18 19 19 20 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, Liabilities 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

	Organizations that follow FASB ASC 958, check here ▶ □ and complete lines 27, 28, 32, and 33.			
27	Net assets without donor restrictions		27	
28	Net assets with donor restrictions		28	
	Organizations that do not follow FASB ASC 958, check here ▶ ☒ and complete lines 29 through 33.			
29	Capital stock or trust principal, or current funds		29	
30	Paid-in or capital surplus, or land, building, or equipment fund		30	
31	Retained earnings, endowment, accumulated income, or other funds	545,459.	31	657,077.
32	Total net assets or fund balances	545,459.	32	657,077.
33	Total liabilities and net assets/fund balances	552,903.	33	662,607.

Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X 

5,530.

5,530.

7,444.

7,444.

25

26

D	4	2
rage	1	4

				, ago
Par	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	32	3,008.
2	Total expenses (must equal Part IX, column (A), line 25)	2	21	1,390.
3	Revenue less expenses. Subtract line 2 from line 1	3	11	1,618.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	54.	5,459.
5	Net unrealized gains (losses) on investments	5		
6	Donated services and use of facilities	6		
7	Investment expenses	7		
8	Prior period adjustments	8		
9	Other changes in net assets or fund balances (explain on Schedule O)	9		
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line	# 7 TV	* * * * * * * *	
	32, column (B))	10	65	7,077.
Part	XII Financial Statements and Reporting			
	Check if Schedule O contains a response or note to any line in this Part XII			🗆
			١	es No
1	Accounting method used to prepare the Form 990: ▼ Cash ☐ Accrual ☐ Other		2	
	If the organization changed its method of accounting from a prior year or checked "Other," e	xplain in		
	Schedule O.			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		2a	×
	If "Yes," check a box below to indicate whether the financial statements for the year were con	npiled or		
	reviewed on a separate basis, consolidated basis, or both:			
	☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis			
b	Were the organization's financial statements audited by an independent accountant?		2b	×
	If "Yes," check a box below to indicate whether the financial statements for the year were audit	ed on a	79.35	
	separate basis, consolidated basis, or both:		(X)	
	☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis			
C	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for over	rsight of		
	the audit, review, or compilation of its financial statements and selection of an independent accounta	nt? .	2c	
	If the organization changed either its oversight process or selection process during the tax year, ex	plain on	gression in	
	Schedule O.			a grange
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set for	th in the	Committee of the Commit	
•	Single Audit Act and OMB Circular A-133?		За	×
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not und	ergo the		
	required audit or audits, explain why on Schedule O and describe any steps taken to undergo such a		3b	
	DEV DOBBINA DDO		Farm.	QQQ (agan)

#### **SCHEDULE A** (Form 990 or 990-EZ)

**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.

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

➤ Attach to Form 990 or Form 990-EZ.

➤ Go to www.irs.gov/Form990 for instructions and the latest information. Name of the organization Employer identification number

Open to Public Inspection

	changiomatosis & Gorham				26-1224181	
Par			··········			ons.
	organization is not a private founda		,		•	
1	A church, convention of churc					
2 3	A school described in section		•		, ,	
, -	A hospital or a cooperative ho					MIN Flatautha
٠4	hospital's name, city, and state		organication with a nost	niai described in	section Tro(b)(1)(A)	ini). Enter the
5	An organization operated for section 170(b)(1)(A)(iv). (Com		college or university	owned or opera	ted by a government	al unit described in
6	A federal, state, or local gover					
7	An organization that normally described in section 170(b)(1)			port from a gove	ernmental unit or fron	n the general public
8	☐ A community trust described i		•	Part II.)		
9	☐ An agricultural research organ			•	n conjunction with a l	and-grant college
-	or university or a non-land-gra university:	nt college of agr	iculture (see instructio	ons). Enter the na	ame, city, and state of	the college or
10	An organization that normally receipts from activities related	to its exempt ful	nctions, subject to ce	rtain exceptions:	and (2) no more than	1331/3% of its
	support from gross investmen acquired by the organization a	t income and uni fter June 30, 197	related business taxal 75. See <b>section 509</b> (a	ble income (less	section 511 tax) from Part III \	businesses
11	An organization organized and					
12	An organization organized and	•	• ,	-		rry out the purposes
	of one or more publicly support					
	Check the box in lines 12a thro	=		· -	•	<u> </u>
а	(( ) )					
	the supported organization supporting organization. Y				the directors or trust	ees of the
b		•			cupported organizati	ion/e) by baying
J	control or management of					
	organization(s). You must					g
c	Type III functionally integ its supported organization					ally integrated with,
d			,	•	• •	orted organization(s)
_	that is not functionally inte					
	requirement (see instructio	ns). <b>You must c</b>	omplete Part IV, Sec	ctions A and D,	and Part V.	
е	Check this box if the organ functionally integrated, or					e II, Type III
f	Enter the number of supported	•	tionally integrated sup	oporting organiza	auon.	
g g		•	orted organization(s).			. []
	(i) Name of supported organization	(ii) EIN	(iii) Type of organization	(iv) Is the organizatio		(vi) Amount of
			(described on lines 1–10 above (see instructions))	listed in your governing document?	ng support (see instructions)	other support (see instructions)
				Yes No		
				Yes No		
(A)						
(B)						
(C)						
(D)						
(E)						
Total						

	(Complete only if you checked the				_	•	alify under
<u> </u>	Part III. If the organization fails to	qualify unde	er the tests lis	sted below, p	lease comple	te Part III.)	
	on A. Public Support	(-) 0040	#N 0047	(-) 0040	7 B 0040	(1) 0000	(A) T . 1 . 1
Caren 1	dar year (or fiscal year beginning in)  Gifts, grants, contributions, and	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
•	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.	r				* 4	
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						
	on B. Total Support						
	dar year (or fiscal year beginning in)	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(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					12	
13	First 5 years. If the Form 990 is for the	organization'	s first, second	l, third, fourth,	or fifth tax ye	ear as a section	on 501(c)(3)
<u> </u>	organization, check this box and stop he	re .					🕨 🔲
	on C. Computation of Public Suppor			11		144	
14 15	Public support percentage for 2020 (line 6 Public support percentage from 2019 Sci					15	<u>%</u> %
16a	331/3% support test—2020. If the organi					L	
	box and stop here. The organization qua						
b	331/3% support test—2019. If the organithis box and stop here. The organization						nore, check
17a	10%-facts-and-circumstances test—2010% or more, and if the organization metal Part VI how the organization meets the organization	eets the facts facts-and-circ	s-and-circumst cumstances te	ances test, ch st. The organi	eck this box a	and stop here	. Explain in
b	10%-facts-and-circumstances test—20 15 is 10% or more, and if the organization in Part VI how the organization meets the organization	on meets the facts-and-ci	acts-and-circu	mstances test est. The organ	, check this bo	x and stop he	re. Explain
18	Private foundation. If the organization instructions				, 17a, or 17b,	check this be	

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

#### 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.)

Secti	on A. Public Support					<b>-</b>	
Caler	dar year (or fiscal year beginning in) 🕨	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1	Gifts, grants, contributions, and membership fees						
_	received. (Do not include any "unusual grants.")	110,897.	46,726.	117,135.	315,738.	321,259.	911,755.
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						
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	<b>Total.</b> Add lines 1 through 5	110,897.	46,726.	117,135.	315,738.	321,259.	911,755.
7a	Amounts included on lines 1, 2, and 3 received from disqualified persons						
b	Amounts included on lines 2 and 3						
ນ	received from other than disqualified						
	persons that exceed the greater of \$5,000						
	or 1% of the amount on line 13 for the year						
С	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from					A STATE	
	line 6.)						911,755.
	on B. Total Support	430040	<b>6</b> ) 00.1 m		(2) == :=	1	
Galen 9	dar year (or fiscal year beginning in) Amounts from line 6	(a) 2016 110, 897.	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
10a	Gross income from interest, dividends,	110,897.	46,726.	117,135.	315,738.	321,259.	911,755.
IVE	payments received on securities loans, rents,				:		
	royalties, and income from similar sources .	5,071.	7,928.	5,890.	4,316.	1,749.	24,954.
b	Unrelated business taxable income (less	- ,				, v. 13 v	
	section 511 taxes) from businesses						
	acquired after June 30, 1975						
C	Add lines 10a and 10b	5,071.	7,928.	5,890.	4,316.	1,749.	24,954.
11	Net income from unrelated business						
	activities not included in line 10b, whether or not the business is regularly carried on	]				•	
10							
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.)	115,968.	54,654.	123,025.	320,054.	323,008.	936,709.
14	First 5 years. If the Form 990 is for the						
<u> </u>	organization, check this box and stop he						🕨 🗌
3ecu	on C. Computation of Public Suppor Public support percentage for 2020 (line 8			10 ook maa (6)		15	07 24 14
16	Public support percentage from 2019 Sch						97.34 % 95.94 %
	on D. Computation of Investment In				• • • • •	IV	JJ. J4 70
17	Investment income percentage for 2020 (			y line 13, colu	mn (f)) , , ,	17	2.66 %
18	Investment income percentage from 2019						4.06 %
19a	331/3% support tests-2020. If the organ						%, and line
	17 is not more than 331/3%, check this box						
b	33 <sup>1</sup> / <sub>3</sub> % support tests – 2019. If the organization 18 is not more than 331 <sub>2</sub> % check this l						•
20	line 18 is not more than 331/3%, check this l						
20	Private foundation. If the organization di	u noi check a l	JUX ON IINE 14,	, 19a, or 19b, C	HECK THIS DOX	and see instru	ctions 🕨 🗌

#### Part IV Supporting Organizations

(Complete only if you checked a box in line 12 on 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

- 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.
- 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? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 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 in 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 in 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	V Supporting Organizations (continued)	
11 a	Has the organization accepted a gift or contribution from any of the following persons?  A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization?  A family member of a person described in line 11a above?	Yes No  11a  11b
	A 35% controlled entity of a person described in line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide detail in <b>Part VI.</b>	11c
Secti	on B. Type I Supporting Organizations	·
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 <b>Part VI</b> 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.	Yes No
2 Casti	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.  on C. Type II Supporting Organizations	2
Secu	on 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 <b>Part VI</b> how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).	1
Secti	on D. All Type III Supporting Organizations	
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?	Yes No
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 <b>Part VI</b> how the organization maintained a close and continuous working relationship with the supported organization(s).	2
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? If "Yes," describe in <b>Part VI</b> the role the organization's supported organizations played in this regard.	3
Secti	on 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 b c 2	<ul> <li>☐ The organization satisfied the Activities Test. Complete line 2 below.</li> <li>☐ The organization is the parent of each of its supported organizations. Complete line 3 below.</li> <li>☐ The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity Activities Test. Answer lines 2a and 2b below.</li> </ul>	(see instructions).  Yes No
а	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 <b>Part VI identify</b> 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
Ь	Did the activities described in 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 <b>Part VI</b> 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 a	Parent of Supported Organizations. <i>Answer lines 3a and 3b below</i> .  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> .	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 <b>Part VI</b> the role played by the organization in this regard.	3b

Part	Type III Non-Functionally Integrated 509(a)(3) Supporting Org	jani	zations	
1	Check here if the organization satisfied the Integral Part Test as a qualifying instructions. All other Type III non-functionally integrated supporting organ			ons A through E.
Sect	ion 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		
	Other expenses (see instructions)	7		
8	Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)	8		
Sect	ion B-Minimum Asset Amount	100000	(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		
е	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		
Secti	ion 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	(Mary Mary Mary Mary Mary Mary Mary Mary	4:
7	Check here if the current year is the organization's first as a non-functional (see instructions).	ally	integrated Type III suppoi	ting organization

Schedule A (Form 990 or 990-EZ) 2020

Part	V Type III Non-Functionally Integrated 509(a)(3	3) Supporting Organi	zations (continue	(d)	
Sect	ion D—Distributions				Current Year
1	Amounts paid to supported organizations to accomplish			1	
2	Amounts paid to perform activity that directly furthers exe	empt purposes of suppo	rted		
	organizations, in excess of income from activity			2	
3	Administrative expenses paid to accomplish exempt purp	oses of supported orga	nizations	3	
4	Amounts paid to acquire exempt-use assets			4	
5	Qualified set-aside amounts (prior IRS approval required-		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	th the organization is res	ponsive		
	(provide details in Part VI). See instructions.			8	
9	Distributable amount for 2020 from Section C, line 6			9	
10	Line 8 amount divided by line 9 amount	<del></del>	<b>7-1</b> 1	10	
Secti	ion E—Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistribution Pre-2020	ns	(iii) Distributable Amount for 2020
1	Distributable amount for 2020 from Section C, line 6			V. V.	
2	Underdistributions, if any, for years prior to 2020				
	(reasonable cause required - explain in Part VI). See				
	instructions.				
3	Excess distributions carryover, if any, to 2020				
a	From 2015				
b	From 2016			ř.	
С	From 2017				
d	From 2018				
е	From 2019				
f	Total of lines 3a through 3e				
g	Applied to underdistributions of prior years			- 1.720 - 1.72	
h	Applied to 2020 distributable amount				The State of the State of the Western
<u>i</u>	Carryover from 2015 not applied (see instructions)				
<u> </u>	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.				
4	Distributions for 2020 from				
	Section D, line 7: \$			nagori Marau	
a	Applied to underdistributions of prior years				
b	Applied to 2020 distributable amount  Remainder. Subtract lines 4a and 4b from line 4.				
				200	
5	Remaining underdistributions for years prior to 2020, if		•	8	
	any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in <b>Part VI</b> . See instructions.			ı	
6	Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in				
	Part VI. See instructions.				
7	Excess distributions carryover to 2021. Add lines 3j				74. (25.2777 <b>0</b> 783 <b>0</b> 502.84846303578
•	and 4c.				
8	Breakdown of line 7:				
<u>о</u> а	Excess from 2016				
<u>a</u>	Excess from 2017			3). 	
C	Excess from 2018				ana ar in sanan kenti da ar ar ar isalah da kenti da ar ar ar isalah da kenti da ar ar ar isalah da ar ar ar a Baran baran ba
d	Excess from 2019				
	Excess from 2020				

Schedule A (Form 990 or 990-EZ) 2020

Part VI	III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c B, lines 1 and 2; Part IV, Section C, line 1; Par	anations required by Part II, line 10; Part II, line 17a or 17b; Part 2, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section t IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, ne 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, ny additional information. (See instructions.)
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#### SCHEDULE D (Form 990)

#### **Supplemental Financial Statements**

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

OMB No. 1545-0047

Open to Public Inspection

Internal Revenue Service

► Attach to Form 990.

Department of the Treasury ➤ Go to www.irs.gov/Form990 for instructions and the latest information. Employer identification number Name of the organization Lymphangiomatosis & Gorham's Disease Alliance, Inc. 26-1224181 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 Total number at end of year . . . . . . . . . 1 Aggregate value of contributions to (during year) . 2 Aggregate value of grants from (during year) . . . 3 4 Aggregate value at end of year . . . . . . . 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 Conservation Easements. Part II Complete if the organization answered "Yes" on Form 990, Part IV, line 7. Purpose(s) of conservation easements held by the organization (check all that apply). Preservation of land for public use (for example, recreation or education) Protection of natural habitat Preservation of a certified historic structure Preservation of open space Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year. Held at the End of the Tax Year 2a 2b Number of conservation easements on a certified historic structure included in (a) . . . . 2c Number of conservation easements included in (c) acquired after 7/25/06, and not on a 2d Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the 3 tax year ► Number of states where property subject to conservation easement is located ▶ 4 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year 6 7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year 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)? 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. Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

#### Part III

- 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.
- 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:
- 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:
- Assets included in Form 990, Part X . . . . . . . .

Part		Organizations Maintaining	Collections of	Art, His	torical T	reasures, c	r Ot	her Similar Ass	sets (cor	itinue	ed)
3		g the organization's acquisition, action items (check all that apply):	accession, and ot								
a	☐ Pt	ublic exhibition		d	☐ Loan	or exchange p	orogr	am			
b	☐ Sc	cholarly research		e	☐ Other						
c	☐ Pr	eservation for future generations									
4		de a description of the organizat		and expl	ain how ti	hey further the	e org	janization's exem	pt purpos	ie in	Part
5		g the year, did the organization s to be sold to raise funds rather	than to be mainta								No
Part	ĮV.	<b>Escrow and Custodial Arra</b>	ingements.								
		Complete if the organization 990, Part X, line 21.						·		−orm	1
1a		e organization an agent, trustee, ded on Form 990, Part X?							t □ Yes		No
b	If "Ye	s," explain the arrangement in Pa	art XIII and comple	ete the fo	ollowing ta	able:		Λ.	nount		
_	Dogir	ning holonoo					4 -		HOUFIE		
C	_	nning balance					10				
d		ions during the year					1d				
e		butions during the year					1e				
f		ng balance					1f				
2a		ne organization include an amour								Щ	No
b		s," explain the arrangement in Pa	art XIII. Check her	e if the e	xplanatio	n has been pr	ovide	ed on Part XIII .			
Pari	V	Endowment Funds.									
		Complete if the organization									
			(a) Current year	(b) Pri	or year	(c) Two years t	pack	(d) Three years back	(e) Four y	ears b	ack
1a	Begir	ning of year balance									
b	Conti	ributions									
С		nvestment earnings, gains, and s									
d	Grant	s or scholarships							-		
e		expenditures for facilities and									
		ams									
f		nistrative expenses									
g		of year balance									
2		de the estimated percentage of t	ha aurrant vaar on	d balanc	o (lino 1a	column (a)) i			<u> </u>		
					e lii ie 19	, column (a)) i	leiu i	a5.			
a	Dorm	d designated or quasi-endowmer	0/	70							
b		anent endowment	%								
С		endowment ▶ %	m	000/							
2-		ercentages on lines 2a, 2b, and the									
3a		nere endowment funds not in the rization by:	e possession of tr	ie organi	zation tha	at are neid an	a aa	ministered for the	F		
	-	•								es	No
		nrelated organizations							3a(i)		
		•							3a(ii)		
b		s" on line 3a(ii), are the related or	•						3b		
4		ibe in Part XIII the intended uses		on's endo	owment fu	ınds.					
Part	VI	Land, Buildings, and Equip									
		Complete if the organization	answered "Yes	" on For	m 990, F	Part IV, line 1	l1a.	See Form 990,	Part X, li	ne 10	O
		Description of property	(a) Cost or ot (investm		, , ,	r other basis ther)		Accumulated epreciation	(d) Book	value	
4.~	lacal		(								
1a	Land		•								
b		ngs	-								
		ehold improvements	•								
d		ment	•								····-
е	Other										
i otal.	Add lii	nes 1a through 1e. (Column (d) m	nust equal Form 9:	90 Part	X column	(B) line 10c	}	<b>&gt;</b>			

Part VII	Investments—Other Securities.	000 Doubly Say	14b Cas Fama 000 Dad V Hand 10
	Complete if the organization answered "Yes" on For		
	(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) Financia	derivatives		
	neld equity interests		
(3) Other			
<u>(^)</u>	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~		
(B)	***************************************		
(C)			
			,
<u>(F)</u>			
(G)			
(H)	mn (b) must equal Form 990, Part X, col. (B) line 12.) . ▶		
Part VIII	Investments—Program Related.		
rait viii	Complete if the organization answered "Yes" on For	m 000 Port IV line	a 11a Cas Form 000 Port V line 12
	(a) Description of investment		
	(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)			
	mn (b) must equal Form 990, Part X, col. (B) line 13.) . 🕨		
Part IX	Other Assets.		
	Complete if the organization answered "Yes" on For	m 990, Part IV, line	e 11d. See Form 990, Part X, line 15.
	(a) Description		(b) Book value
(1) Charle	es Scwab Investment Account		129,867.
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Part X	mn (b) must equal Form 990, Part X, col. (B) line 15.) Other Liabilities.		▶   129,867.
	Complete if the organization answered "Yes" on For line 25.	m 990, Part IV, line	e 11e or 11f. See Form 990, Part X,
1.	(a) Description of liability		(b) Book value
(1) Federal in			,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,
	Liabilities		5,160.
	can Express Credit Card		370.
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
	mn (b) must equal Form 990, Part X, col. (B) line 25.)		· · · · · <b>&gt;</b> 5,530.
2. Liability for	uncertain tax positions. In Part XIII, provide the text of the footnot	ote to the organization	's financial statements that reports the
organization's	s liability for uncertain tax positions under FASB ASC 740. Check	here if the text of the	footnote has been provided in Part XIII . $\hfill \Box$

Part	XI Reconciliation of Revenue per Audited Financial Statem	ents With Revenue pe	r Return.
	Complete if the organization answered "Yes" on Form 990,	•	
1	Total revenue, gains, and other support per audited financial statements		1
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
а	Net unrealized gains (losses) on investments	2a	
b	Donated services and use of facilities	2b	
С	Recoveries of prior year grants		
d	Other (Describe in Part XIII.)		
е	Add lines 2a through 2d		2e
3	Subtract line 2e from line 1		3
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
а	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)		
С	Add lines <b>4a</b> and <b>4b</b>		4c
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line		
Part	XII Reconciliation of Expenses per Audited Financial Stater	nents With Expenses p	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
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
а	Donated services and use of facilities	2a	
b	Prior year adjustments	2b	
C	Other losses	2c	
d	Other (Describe in Part XIII.)		
е	Add lines 2a through 2d		2e
3	Subtract line <b>2e</b> from line <b>1</b>		3
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
а	Investment expenses not included on Form 990, Part VIII, line 7b		
b	Other (Describe in Part XIII.)	4b	
С	Add lines <b>4a</b> and <b>4b</b>		
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, lin	ne 18.)	5
	XIII Supplemental Information.		
	e the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a ar XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part		
د, ۱ CLII	Al, illes 20 and 40, and t art All, illes 20 and 40. Also complete this part	to provide any additional	inomation.
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Schedule D (Fo	chedule D (Form 990) 2020 Page <b>5</b>							
Part XIII	Supplemental Information (continued)							
		***************************************						
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	***************************************							
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		***************************************						
•••••		***************						
	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~							

#### **SCHEDULE F** (Form 990)

### **Statement of Activities Outside the United States**

OMB No. 1545-0047

2020

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

► Complete if the organization answered "Yes" on 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.

Employer identification number

_ymr	phangiomatosis & Gorh	am's Dis	ease Allia	ance, Inc.	26-122	4181
Par	General Information Form 990, Part IV, line		ies Outside	the United States. Com	plete if the organization a	inswered "Yes" on
1	For grantmakers. Does the other assistance, the grante award the grants or assistance	es' eligibility	for the grant	ts or assistance, and the s	selection criteria used to	☐ Yes ☐ No
2	For grantmakers. Describe outside the United States.	in Part V the	e organization	's procedures for monitorin	g the use of its grants an	d other assistance
3	Activities per Region. (The fo	llowing Part	l, line 3 table o	can be duplicated if addition	al 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 the 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	Subtotal					
b	Total from continuation sheets to Part I					

c Totals (add lines 3a and 3b)

Page 2	n answered "Yes" on Form 990 d.
Schedule F (Form 990) 2020	artil 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.
Sche	

-	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	( <b>d</b> ) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(j) Method of valuation (book, FMV, appraisal, other)
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7	Enter total nu exempt 501(c)	umber of recipie )(3) organization	ent organizations list by the IRS, or for v	Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter •	ecognized as che ounsel has provid	arities by the foreign ed a section 501(c)(3)	country, recognized equivalency letter	as a tax	
က	Enter total nui	mber of other or	Enter total number of other organizations or entities	lies				<b>▲</b>	200 (200 mm c 2) 11 c fripe

REV 09/08/21 PRO

Page 3

Schedule F (Form 990) 2020

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.

Schedule F (Form 990) 2020 (h) Method of valuation (book, FMV, appraisal, other) (g) Description of noncash assistance (f) Amount of noncash assistance (e) Manner of cash disbursement wire 10,565. (d) Amount of cash grant REV 09/08/21 PRO (c) Number of recipients Н (b) Region Europe (a) Type of grant or assistance (1) Research (11) (17) BAA 3 0 (10) (12) (13) (14) (15) (16) (18) <u>N</u> ල <u>(2</u>) 9 6 <u>®</u>

Schedule F (Form 990) 2020

BAA

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)	☐ <b>Ye</b> s	⊠ 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

REV 09/08/21 PRO

Part V	Supplemental Information  Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.
************	
***************************************	

SCHEDULE I (Form 990) Department of the Treasury Internal Revenue Service Name of the organization

N

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

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

▶ Attach to Form 990.

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Employer identification number

**№** XYes 26-1224181 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 gratits or assistance?

Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States. Inc. Lymphangiomatosis & Gorham's Disease Alliance, the selection criteria used to award the grants or assistance? General Information on Grants and Assistance Part I

Part II		ssistance to Dor y recipient that r	mestic Organiza eceived more th	ations and Dom an \$5,000. Part	l <b>estic Governm</b> Il can be duplica	ents. Complete if ated if additional s	the organization answapace is needed.	Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.
1 (a)	(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 (f) Method of valuation (f) Most population (f) Method of valuation (f) Method	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) Un Univer	(1) University of PA University of PA Philadelphia PA 19104	23-1352685		27,000.				research
(2) UI 1501	(2) UpLift Athletes 1501 NE Qulet Rd In Bend OR 97701	84-2742738		10,000.				program
<u>(c)</u>								
<b>4</b>								
<u>(2</u> )								
(9)								
(7)								
(8)								
(6)								
(10)								
(11)								
(12)								
0 B	Enter total number of section 501(c)(3) and government organizations listed in the line 1 table Enter total number of other organizations listed in the line 1 table	501(c)(3) and goverganizations listed	ernment organizati in the line 1 table	ions listed in the line 1 table	ne 1 table			<b>.</b>

REV 09/08/21 PRO For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) 2020

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Schedule I (Form 990) 2020

Part III

Schedule I (Form 990) 2020 (f) Description of noncash assistance Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information. 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. (e) Method of valuation (book, FMV, appraisal, other) (d) Amount of noncash assistance (c) Amount of cash grant (b) Number of recipients (a) Type of grant or assistance Part IV 0 က 4 S 9

#### **SCHEDULE O** (Form 990 or 990-EZ)

Department of the Treasury

#### 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 Open to Public Inspection

Internal Revenue Service Name of the organization Employer identification number Lymphangiomatosis & Gorham's Disease Alliance, Inc. 26-1224181 Pt VI, Line 7a: President Pt VI, Line 8b: notes taken Pt VI, Line 11b: officer review Pt VI, Line 12c: Notes taken at board meeting Pt VI, Line 19: upon request