Short Form Return of Organization Exempt From Income Tax

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

2018

OMB No. 1545-1150

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/Form990EZ for instructions and the latest information.

Open to Public Inspection

A	For the	e 2018 calendar year, or tax year beginning ${ m Jul} \ 1$, 2018, and ending	Jun 30	,2019
В	Check if	applicable: C Name of organization D En	···	ication number
	Address		5-122418	1
\vdash	Name cl	hange Number and street (or P.O. box, if mail is not delivered to street address) Room/suite E Tel	ephone numbe	er
\vdash	Initial ret	19919 VIIIa Lante Place	561)441-	9766
	Amende	City or fown state or province country, and 710 and 71	oup Exempti	·····
		. Paga Datan DT 22424	umber ►	
G	Accour			organization is no
	Websit	re: ► N/A	ed to attach	
j ·	Tax-exe		990, 990-EZ	
		f organization: Corporation Trust Association Other		., 01 000 11 7.
L,	Add line	es 5b, 6c, and 7b to line 9 to determine gross receipts. If gross receipts are \$200,000 or more, or if total accept	<u> </u>	
(Pa	art II, co	olumn (B)) are \$500,000 or more, file Form 990 instead of Form 990-EZ	→ _	100 005
E	art I	Revenue, Expenses, and Changes in Net Assets or Fund Balances (see the instru	ections for	123,025.
		Check if the organization used Schedule O to respond to any question in this Part I	101 61 101101	raiti)
	1	Contributions, gifts, grants, and similar amounts received	11	<u>A</u>
	2	Program service revenue including government fees and contracts		117,135.
	3	Membership dues and assessments	2	7/1
	4	Investment income	3	~ 0.00
	5a	Gross amount from selections at the state of	4	5,890.
	b		4-1	
	C	Gain or (loss) from sale of experts other than inventors (Outstand Burnellin Electrical Burne		
	6	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a) Gaming and fundraising events:	5c	
ē	a	Gross income from gaming (attach Schedule G if greater than \$15,000)		
ž	_	Oa j		
Revenue	b	Gross income from fundraising events (not including \$ of contributions		
Œ		from fundraising events reported on line 1) (attach Schedule G if the sum of such gross income and contributions exceeds \$15,000) 6b		
		· +		
	d	Less: direct expenses from gaming and fundraising events 6c		
	d	Net income or (loss) from gaming and fundraising events (add lines 6a and 6b and subtract line 6c)		
	 _		6d	
	7a	Gross sales of inventory, less returns and allowances		
	b	Less: cost of goods sold		
	C	Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a)	7c	
	8	Other revenue (describe in Schedule O)	8	
	9	Total revenue. Add lines 1, 2, 3, 4, 5c, 6d, 7c, and 8	9	123,025.
	10	Grants and similar amounts paid (list in Schedule O)	10	
/ 0	11	Benefits paid to or for members	11	
Ses	12	Salaries, other compensation, and employee benefits	12	
e	13	Professional fees and other payments to independent contractors	13	1,875.
Expenses	14	Occupancy, rent, utilities, and maintenance	14	409.
ш	15	Printing, publications, postage, and shipping	15	5,501.
	16	Other expenses (describe in Schedule O)	16	123,881.
	17	Total expenses. Add lines 10 through 16	17	131,666.
ţ	18	Excess of (deficit) for the year (Subtract line 17 from line 9)	18	-8,641.
SSE	19	Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with		
Net Assets		end-of-year figure reported on prior year's return)	19	346,681.
Se	20	Other changes in net assets or fund balances (explain in Schedule O)	20	
-	21	Net assets or fund balances at end of year. Combine lines 18 through 20	21	338,040.

	rt II Balance Sheets (see the instructions					
	Check if the organization used Schedul	e O to respond to a	ny question in this			
				(A) Beginning of year	-	(B) End of year
22	Cash, savings, and investments			182,453.	22	162,228.
23	Land and buildings				23	
24	Other assets (describe in Schedule O)				24	184,519.
25	Total assets				25	346,747.
26	Total liabilities (describe in Schedule O)				26	8,707.
27	Net assets or fund balances (line 27 of colum III Statement of Program Service Accon				27	338,040.
Par				,		Expenses
Mba	Check if the organization used Schedule				(Rea	uired for section
	t is the organization's primary exempt purpose?				501(c)(3) and 501(c)(4)
as n	cribe the organization's program service accomple neasured by expenses. In a clear and concise rons benefited, and other relevant information for e	nanner, describe the	f its three largest p e services provided	rogram services, , the number of	orga	nizations; optional for rs.)
28	Worldwide patient support program	n which	· · · · · · · · · · · · · · · · · · ·			
	includes a website with rare dies a patient discussion forum.	sease info				
	(Grants \$ 0.) If this amoun	t includes foreign gra	ents, check here	> [7]	28a	121,879.
29	7.1.1.0					121,013.

	(Grants \$) If this amount	t includes foreign gra	ints, check here	▶ □	29a	
30	-		·-·			
				1		
	(Grants \$) If this amoun	t includes foreign gra	nts, check here .	▶ □	30a	
31	Other program services (describe in Schedule O)				***************************************	
	(Grants \$) If this amount	t includes foreign gra	nts, check here .	▶ 🗀 🕆	31a	
	Total program service expenses (add lines 28a				32	121,879.
Par					nstruc	tions for Part IV)
	Check if the organization used Schedule	 O to respond to as 	av augetion in thie I	Dow 11/		🗆
					<u></u>	<u></u>
	(a) Name and title	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe	ee (e)	····
Joh	-	(b) Average hours per week	(c) Reportable compensation (Forms W-2/1099-MISC)	(d) Health benefits, contributions to employe benefit plans, and	ee (e)	Estimated amount of
	(a) Name and title	(b) Average hours per week	(c) Reportable compensation (Forms W-2/1099-MISC)	(d) Health benefits, contributions to employe benefit plans, and	o (e) !	Estimated amount of ther compensation
Pre	(a) Name and title	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	o (e) !	Estimated amount of
Pre Sco	(a) Name and title n Kelly s/Acting Secretary	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	o (e) !	Estimated amount of ther compensation
Pre Sco Cha All	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	o (e) !	Estimated amount of ther compensation
Pre Sco Cha All Dir	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	o (e) !	Estimated amount of ther compensation
Pre Sco Cha All Dir Sco	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb	(b) Average hours per week devoted to position 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	o (e) !	Estimated amount of ther compensation 0.
Pre Sco Cha All Dir Sco Dir	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector	(b) Average hours per week devoted to position 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	(e) (o)	Estimated amount of ther compensation 0.
Pre Sco Cha All Dir Sco Dir San	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb	(b) Average hours per week devoted to position 30.00 5.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	(e) (o)	Estimated amount of ther compensation 0. 0.
Pre Sco Cha All Dir Sco Dir San Vic	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President	(b) Average hours per week devoted to position 30.00 5.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	(e) (o)	Estimated amount of ther compensation 0. 0.
Pre Sco Cha All Dir Sco Dir San Vic Lis	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper	(b) Average hours per week devoted to position 30.00 5.00 5.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	(e) (o)	Estimated amount of ther compensation 0. 0. 0.
Pre Sco Cha All Dir Sco Dir San Vic Lis Dir	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector	(b) Average hours per week devoted to position 30.00 5.00 5.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	ee (e)	Estimated amount of ther compensation 0. 0. 0.
Pre Sco Cha All Dir Sco Dir San Vic Lis Dir	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector fany Ferry	(b) Average hours per week devoted to position 30.00 5.00 5.00 5.00 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation	ee (e)	Estimated amount of ther compensation 0. 0. 0. 0.
Pre Sco Cha All Dir Sco Dir San Vic Lis Dir Tif	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector fany Ferry	(b) Average hours per week devoted to position 30.00 5.00 5.00 5.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation		Estimated amount of ther compensation 0. 0. 0. 0.
Pre Sco Cha All Dir Sco Dir San Vic Lis Dir Tif	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector fany Ferry ector ch Maersch	(b) Average hours per week devoted to position 30.00 5.00 5.00 5.00 30.00 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation		Estimated amount of ther compensation 0. 0. 0. 0. 0.
Pre Sco Cha All Dir Sco Dir San Vic Lis Dir Tif	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector fany Ferry	(b) Average hours per week devoted to position 30.00 5.00 5.00 5.00 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation		Estimated amount of ther compensation 0. 0. 0. 0. 0.
Pre Sco Cha All Dir Sco Dir San Vic Lis Dir Tif	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector fany Ferry ector ch Maersch	(b) Average hours per week devoted to position 30.00 5.00 5.00 5.00 30.00 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0. 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation		Estimated amount of ther compensation O. O. O. O. O.
Pre Sco Cha All Dir Sco Dir San Vic Lis Dir Tif	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector fany Ferry ector ch Maersch	(b) Average hours per week devoted to position 30.00 5.00 5.00 5.00 30.00 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0. 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation		Estimated amount of ther compensation O. O. O. O. O.
Pre Sco Cha All Dir Sco Dir San Vic Lis Dir Tif	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector fany Ferry ector ch Maersch	(b) Average hours per week devoted to position 30.00 5.00 5.00 5.00 30.00 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0. 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation		Estimated amount of ther compensation O. O. O. O. O.
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Pre Sco Cha All Dir Sco Dir San Vic Lis Dir Tif	(a) Name and title n Kelly s/Acting Secretary t Weisner irman an Gammon ector tt Goldfarb ector dra Goldfarb e President a Klepper ector fany Ferry ector ch Maersch	(b) Average hours per week devoted to position 30.00 5.00 5.00 5.00 30.00 30.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0. 0. 0.	(d) Health benefits, contributions to employe benefit plans, and deferred compensation		Estimated amount of ther compensation 0. 0. 0. 0. 0.

Par	Other Information (Note the Schedule A and personal benefit contract statement requirement	s in th		age C
	instructions for Part V.) Check if the organization used Schedule O to respond to any question in thi	s Part	٧.	. 🗆
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		Yes	No
34		33		×
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	34		×
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)?	35a		×
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	35b		
С	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	35c		×
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	36		×
37a	Enter amount of political expenditures, direct or indirect, as described in the instructions ▶ 37a			
b	Did the organization file Form 1120-POL for this year?	37b	341494030474	×
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?	38a		×
b	If "Yes," complete Schedule L, Part II and enter the total amount involved			
39	Section 501(c)(7) organizations. Enter:			
a b	Initiation fees and capital contributions included on line 9			
40a	Gross receipts, included on line 9, for public use of club facilities			
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	40b		×
С	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			
d	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax on line 40c reimbursed by the organization			
е	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	40e		×
41	List the states with which a copy of this return is filed ▶			
42a	The organization's books are in care of ▶ John Kelly Telephone no. ▶ (563)	1)441	L-97	66
	Located at ▶ 19919 Villa Lante Place, Boca Raton FL ZIP+4 ▶ 3343	34		
b	At any time during the calendar year, did the organization have an interest in or a signature or other authority over	$\overline{}$	Yes	No
	a financial account in a foreign country (such as a bank account, securities account, or other financial account)? If "Yes," enter the name of the foreign country	42b	tahosenesse s	× econocia
	See the instructions for exceptions and filing requirements for FinCEN Form 114, Report of Foreign Bank and			
	Financial Accounts (FBAR).			
С	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 ▶	42c		<u>×</u>
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		. •	- 🗆
			Yes	No
44a	Did the organization maintain any donor advised funds during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ	44a		×
	Did the organization operate one or more hospital facilities during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ	44b		×
đ	Did the organization receive any payments for indoor tanning services during the year?	44c 44d		×
45a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	45a		×
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	45b		×

					Tes No
46	Did the organization engage, directly or i	ndirectly, in political c	ampaign activities on	behalf of or in oppos	ition
	to candidates for public office? if "Yes,"		Parti		· 46 ×
Part					
	All section 501(c)(3) organization	ns must answer que	stions 47-49b and	52, and complete th	ne tables for lines
	50 and 51.				
	Check if the organization used Sc	hedule O to respond	to any question in the	his Part VI	
					Yes No
47	Did the organization engage in lobbying	activities or have a s	section 501(h) electio	n in effect durina the	tax
	year? If "Yes," complete Schedule C, Par				. 47 ×
48	Is the organization a school as described i				. 48 ×
49a	Did the organization make any transfers t				
b					
50	If "Yes," was the related organization a se				. [49b]
50	Complete this table for the organization's employees) who each received more than	s live nignest compens	sated employees (other	er than officers, direct	fors, trustees, and key
***************************************	employees) who each received more than	T \$100,000 OF COMPER	sation from the organ		ie, enter None.
	(a) Name and this of soul and any	(b) Average	(c) Reportable	(d) Health benefits, contributions to employee	(e) Estimated amount of
	(a) Name and title of each employee	hours per week devoted to position	compensation (Forms W-2/1099-MISC)	benefit plans, and deferred	
		devoted to position	(1 011113 W-2/ 1000-WIGO)	compensation	
na					
na		0.00	0.	0.	0.
	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~				
			······································		
	***************************************				
		A			
	Total number of other employees paid ov	•			
51	Complete this table for the organization	's five highest compe	nsated independent	contractors who eac	h received more than
	\$100,000 of compensation from the orga	inization. If there is no	ne, enter "None."		
	(a) Name and business address of each independ	dent contractor	(b) Type of servi	ice (c	Compensation
			, , , , , , , , , , , , , , , , , , ,		
none					
	**************************************				
					····
	***************************************				
	T-1-1	1 1 1	4400 000		
	Total number of other independent contra			<u> </u>	
52	Did the organization complete Schedu	ile A? <b>Note:</b> All sed	ction 501(c)(3) orgar	nizations must attac	. —
			· · · · · · · · · · · · · · · · · · ·		.▶⊠ Yes ∐ No
Under pe	enalties of perjury, I declare that I have examined this r	eturn, including accompany	ing schedules and stateme	nts, and to the best of my k	nowledge and belief, it is
true, con	rect, and complete. Declaration of preparer (other than	officer is based on all infor	mation of which preparer h	as any knowledge.	
	I MAN / K/h			01/03/202	0
Sign	Signature of office			Date	
Here	Jack Kelly, President				
	Type or print name and title				
Paid	Print/Type preparer's name	Preparer's signature	Dat	e G	] ;, PTIN
	Tarada a mana a mana		01	Oheck L	yed P00647836
Prepa	11 to 1	1 / 1////	, 0 1	, ,	, , 500
		ates CPA Firm	PA PA	Firm's EIN ► 03	-0481340
use (	Pirm's name ► Rubin & Associ Firm's address ► 2080 NW BOCA RAT		PA , BOCA RATON, FL	Firm's EIN ►03 33431 Phone no. (5	-0481340 661)750-8299

# Additional information from your Form 990-EZ: Short Form Return of Organization Exempt from Income Tax

# Form 990-EZ: Short Form Return of Organization Exempt from Income Tax Line 16: Other Expenses

**Continuation Statement** 

Description	Amount
Patient Registry Costs	12,000.
Research Grants	40,745.
Office Supplies	1,953.
Telephone	1,792.
Insurance	1,650.
Confrence, Convention, Meetings, & Tournaments	42,704.
Meals & Entertainment	95.
Travel	22,732.
Licences & Fees	195.
Fundraising Fees	15.
	<b>Total</b> 123,881.

## 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.

➤ Attach to Form 990 or Form 990-EZ.

Open to Public Inspection

Employer identification number

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service Name of the organization

(D)

(E) Total ► Go to www.irs.gov/Form990 for instructions and the latest information.

(C)								
(B)								
(A)								
	(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1–10 above (see instructions))	(iv) is the or listed in you docum	r governing	(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)	
g	Provide the following information	about the supp		T			· · L	
f	functionally integrated, or I Enter the number of supported of		tionally integrated sur	oporting o	rganizati	on.	[	
е	Check this box if the organ	ization received	a written determination	on from th	e IRS th	at it is a Type I, Type	II, Type III	
u	Type III non-functionally integrated that is not functionally integrequirement (see instructionally integrated in the contraction in the contracti	grated. The orga	nization generally mus	st satisfy	a distribu	ition requirement and		
c d	its supported organization(	s) (see instructio	ns). <b>You must comp</b>	lete Part	IV, Secti	ons A, D, and E.	-	
	control or management of organization(s). You must	the supporting o complete Part I	rganization vested in V, Sections A and C.	the same	persons	that control or mana	age the supported	
a b	the supported organization supporting organization. Y	n(s) the power to ou must comple	regularly appoint or e ete Part IV, Sections	lect a ma	jority of t	he directors or truste	ees of the	
12	An organization organized and of one or more publicly support Check the box in lines 12a through	operated exclus orted organizatio ough 12d that des	sively for the benefit on the described in <b>secti</b> scribes the type of sup	f, to perfo i <b>on 509(a</b> ) oporting o	rm the fu (1) or se rganization	unctions of, or to care ection 509(a)(2). See on and complete line	s section 509(a)(3). s 12e, 12f, and 12g.	
11	receipts from activities related support from gross investmen acquired by the organization a   An organization organized and	t income and uni fter June 30, 197	related business taxal 75. See <b>section 509(</b> a	ble incom a <b>)(2).</b> (Con	e (less so nplete Pa	ection 511 tax) from l art III.)	1 331/3% of its businesses	
10	university:  An organization that normally	receives: (1) mor	e than 331/3% of its si	upport fro	m contri	outions, membership	fees, and gross	
9	An agricultural research organ or university or a non-land-gra	ization described	d in section 170(b)(1)	(A)(ix) ope				
8	described in section 170(b)(1)  A community trust described in	(A)(vi). (Complet	te Part II.)		a gover	nmenaruni or ifoli	the general public	
6 7	A federal, state, or local gover	nment or govern					the general number	
5	An organization operated for section 170(b)(1)(A)(iv). (Com	the benefit of a	college or university	owned o	r operate	ed by a government	al unit described in	
3 4	<ul> <li>A hospital or a cooperative ho</li> <li>A medical research organization</li> <li>hospital's name, city, and state</li> </ul>	on operated in co					iii). Enter the	
1 2	A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990 or 990-EZ).)							
	organization is not a private founda		,	-	•	r		
	phangiomatosis & Gorham rt   Reason for Public Cha			comple	te this p	26-1224181 art.) See instructio	ns.	
LAVIN	Dhangiomatoele & Gorbom	'e  }}eoseo	Alliance Inc			( ) ( 1 ) ) ) / / / / / / / / / / / / / / / /		

Par		ations Desci	ibed in Sect	ions 170(b)(1	)(A)(iv) and	170(b)(1)(A)(v	i)
	(Complete only if you checked to Part III. If the organization fails to	he box on line	e 5, 7, or 8 of	Part I or if th	e organizatio	n failed to qu	alify under
Sec	tion A. Public Support	o quality und	er the tests is	stea below, p	ease comple	te Part III.)	
	ndar year (or fiscal year beginning in)	(a) 2014	<b>(b)</b> 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
1	Gifts, grants, contributions, and	(4) 2014	(6) 2013	(6) 2010	(u) 2017	(e) 2018	(i) Total
	membership fees received. (Do not include any "unusual grants.")			Transition of the Control of the Con			
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	1 1 1 1 1 1 1 1 1 1 E	32 - 215 - 215				
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						
	ion B. Total Support						
	ndar year (or fiscal year beginning in)	(a) 2014	<b>(b)</b> 2015	(c) 2016	(d) 2017	<b>(e)</b> 2018	(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 12 13	Total support. Add lines 7 through 10 Gross receipts from related activities, etc. First five years. If the Form 990 is for the			· · · · · · · · · · · · · · · · · · ·	or fifth tax ve	12	n 501(c)(3)
	organization, check this box and stop he						
Secti	on C. Computation of Public Suppor	t Percentag	е				
14	Public support percentage for 2018 (line 6	6, column (f) di	vided by line 1	1, column (f))		14	%
15	Public support percentage from 2017 Sch					15	%
16a	331/3% support test—2018. If the organi box and stop here. The organization qual						
b	331/3% support test—2017. If the organization						
17a	· · · · · · · · · · · · · · · · · · ·						
b	10%-facts-and-circumstances test—20 15 is 10% or more, and if the organiza Explain in Part VI how the organization in supported organization	ition meets the neets the "fact	e "facts-and-c s-and-circums	ircumstances" stances" test.	test, check t The organizati	his box and son qualifies as	a publicly
18	<b>Private foundation.</b> If the organization did instructions	d not check a l	oox on line 13,	16a, 16b, 17a	, or 17b, checl	k this box and	

... . ¥ ......

# 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.)

Sect	tion A. Public Support				· · · · · · · · · · · · · · · · · · ·		
Cale	ndar year (or fiscal year beginning in) 🕨	(a) 2014	<b>(b)</b> 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
1	Gifts, grants, contributions, and membership fees						······
_	received. (Do not include any "unusual grants.")	93,774.	88,067.	110,897.	46,726.	117,135.	456,599.
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		A	to the light has	1.90%		•
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	93,774.	88,067.	110,897.	46,726.	117,135.	456,599.
7a	Amounts included on lines 1, 2, and 3						
	received from disqualified persons .		-				
b	Amounts included on lines 2 and 3						
	received from other than disqualified						
	persons that exceed the greater of \$5,000	j					
	or 1% of the amount on line 13 for the year			:			
C	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from						
A:	line 6.)						456,599.
	on B. Total Support	1					
	idar year (or fiscal year beginning in)	(a) 2014	<b>(b)</b> 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
9	Amounts from line 6	93,774.	88,067.	110,897.	46,726.	117,135.	456,599.
10a	Gross income from interest, dividends,						
	payments received on securities loans, rents, royalties, and income from similar sources.						
<b>L</b>		5,920.	5,502.	5,071.	7,928.	5,890.	30,311.
b	Unrelated business taxable income (less section 511 taxes) from businesses						
	acquired after June 30, 1975						
С	Add lines 10a and 10b	F 000	F F00	E 051	7 000	5 000	
11	Net income from unrelated business	5,920.	5,502.	5,071.	7,928.	5,890.	30,311.
11	activities not included in line 10b, whether						
	or not the business is regularly carried on			:			
12	Other income. Do not include gain or	<del></del>					
1.6	loss from the sale of capital assets						
	(Explain in Part VI.)			İ			
13	Total support. (Add lines 9, 10c, 11,						
'-	and 12.)	99,694.	02 560	115 000	E4 CE4	100 005	406 010
14	First five years. If the Form 990 is for the		93,569. s first, secon	115,968.	or fifth tay ve	123,025.	486,910.
	organization, check this box and stop he				· ·		
Secti	on C. Computation of Public Suppor						
15	Public support percentage for 2018 (line 8			3, column (fl)		15	93.77 %
16	Public support percentage from 2017 Sch	nedule A. Part II	II. line 15			16	93.94 %
	on D. Computation of Investment In	come Percen	tage			1 1	
17	Investment income percentage for 2018 (			y line 13, colu	mn (f))	17	6.23 %
18	Investment income percentage from 2017					18	6.06 %
19a	331/3% support tests-2018. If the organ	ization did not	check the box	on line 14, ar	nd line 15 is m		6, and line
	17 is not more than 331/3%, check this box						
b	331/3% support tests - 2017. If the organiz						
	line 18 is not more than 331/3%, check this I						
20	Private foundation. If the organization di	d not check a b	ox on line 14.	19a, or 19b, c	heck this box	and see instruc	_

#### Part IV Supporting Organizations

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

#### **Section A. All Supporting Organizations**

- 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 (b) and (c) 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 12a or 12b in Part I, answer (b) and (c) 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.
- Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in **Part VI**, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).
- **b** Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?
- c Substitutions only. Was the substitution the result of an event beyond the organization's control?
- 6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI.
- 7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (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 77 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 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.)

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Pari	Supporting Organizations (continued)		'	age
		,	Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?			
a	, and a second and			
£_	below, the governing body of a supported organization?	11a		
b		11b	~	
Soot	A 35% controlled entity of a person described in (a) or (b) above? If "Yes" to a, b, or c, provide detail in Part VI. ion B. Type I Supporting Organizations	11c		L
Seci	ion b. Type i Supporting Organizations		.,	
1	Did the directors tructors or membership of one or more compared againsticate here they are not to		Yes	No
•	Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the			
	tax year? 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,		1.3	
	describe how the powers to appoint and/or remove directors or trustees were allocated among the supported			
	organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	1		
2	Did the organization operate for the benefit of any supported organization other than the supported	7.5		
	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	CHATAGORA III	
Sect	ion 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		
Sect	ion D. All Type III Supporting Organizations	<del></del>		
	Distance where the state of the	UNASSAURE III	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?		6035	
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported	38.30.0		
_	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 (2), 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	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	CO. Indiana
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	instruc	tions	s).
а	The organization satisfied the Activities Test. Complete <b>line 2</b> below.			
b	☐ The organization is the parent of each of its supported organizations. Complete line 3 below.			
C	☐ The organization supported a governmental entity. Describe in Part VI how you supported a government entity			~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~
2	Activities Test. Answer (a) and (b) below.	Continues to	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>		ija.	
	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.	0-		
b	·	2a		
5	Did the activities described in (a) 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		BY MADE SA
3	Parent of Supported Organizations. Answer (a) and (b) below.	2D	6/19/4	<b>30000</b>
а	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? Provide details in <b>Part VI</b> .	3a		
b	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each	700		
	of its supported organizations? If "Yes," describe in <b>Part VI</b> the role played by the organization in this regard.	3b	secuses.	SECTION SECTION

instructions).

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organical	aan	izations	
1 Check here if the organization satisfied the Integral Part Test as a qualifying	-		n in Part VI\ See
instructions. All other Type III non-functionally integrated supporting organ			
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	1	
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	to 🔩 - Constant	
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>b</b> Average monthly cash balances	1b		
c Fair market value of other non-exempt-use assets	1c		
d Total (add lines 1a, 1b, and 1c)	1d		
e Discount claimed for blockage or other factors (explain in detail in Part VI):			
2 Acquisition indebtedness applicable to non-exempt-use assets	2		
3 Subtract line 2 from line 1d.	3		
4 Cash deemed held for exempt use. Enter 1-1/2% 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 .035.	6		
7 Recoveries of prior-year distributions	7		
8 Minimum Asset Amount (add line 7 to line 6)	8		
Section C-Distributable Amount			Current Year
1 Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2 Enter 85% of line 1.	2		
3 Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4 Enter greater of line 2 or line 3.	4		
5 Income tax imposed in prior year	5		
6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6		
7 Check here if the current year is the organization's first as a non-functional	lv in	tegrated Type III supporting	g organization (see

Schedule A (Form 990 or 990-EZ) 2018

Part	Type III Non-Functionally Integrated 509(a)(3	3) Supporting Organ	izations (continued)	
Sect	Current Year			
1				
2	Amounts paid to perform activity that directly furthers exe organizations, in excess of income from activity	empt purposes of suppo	orted	
3	Administrative expenses paid to accomplish exempt purp	oses of supported orga	nizations	
4	Amounts paid to acquire exempt-use assets			
5	Qualified set-aside amounts (prior IRS approval required)			
6	Other distributions (describe in Part VI). See instructions.			
7	Total annual distributions. Add lines 1 through 6.			
8	Distributions to attentive supported organizations to whic (provide details in <b>Part Vi</b> ). See instructions.	h the organization is res	spońsive	
9	Distributable amount for 2018 from Section C, line 6			
10	Line 8 amount divided by line 9 amount			
Sect	ion E—Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2018	(iii) Distributable Amount for 2018
1	Distributable amount for 2018 from Section C, line 6			
2	Underdistributions, if any, for years prior to 2018 (reasonable cause required—explain in <b>Part VI</b> ). See instructions.			
3	Excess distributions carryover, if any, to 2018			
а	From 2013			
b	From 2014			
С	From 2015			
d	From 2016			
е	From 2017			
f	Total of lines 3a through e			
g	Applied to underdistributions of prior years			
<u>h</u>	Applied to 2018 distributable amount			
<u>i</u>	Carryover from 2013 not applied (see instructions)			
j	Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4	Distributions for 2018 from Section D, line 7: \$			
a	Applied to underdistributions of prior years			
b	Applied to 2018 distributable amount			
C	Remainder. Subtract lines 4a and 4b from 4.			
5	Remaining underdistributions for years prior to 2018, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in <b>Part VI.</b> See instructions.			
6	Remaining underdistributions for 2018. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in <b>Part VI.</b> See instructions.			
7	Excess distributions carryover to 2019. Add lines 3j and 4c.	en e		
8	Breakdown of line 7:			
a	Excess from 2014			
b	Excess from 2015	4		
С	Excess from 2016			
d	Excess from 2017	and the second second		
6	Excess from 2018	Programme and the second		9 (28)

Schedule A (Form 990 or 990-EZ) 2018

Part VI	III, line 12; Part IV B, lines 1 and 2; I	/, Section A, lin Part IV, Sectior V, line 1; Part V	es 1, 2, 3b, 3d C, line 1; Pai , Section B, li	c, 4b, 4c, 5a, 6, t IV, Section D ne 1e; Part V, S	, 9a, 9b, 9c, 11a , lines 2 and 3; Section D, lines	ne 10; Part II, line 17a a a, 11b, and 11c; Part I Part IV, Section E, line 5, 6, and 8; and Part V e instructions.)	V, Section s 1c, 2a, 2b,
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### SCHEDULE O (Form 990 or 990-EZ)

# 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.

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

► Attach to Form 990 or 990-EZ. ► Go to www.irs.gov/Form990 for the latest information.

ns on	2018			
	Open to Public Inspection			
Employer identification number				

Name of the organization	Employer identification number						
Lymphangiomatosis & Gorham's Disease Alliance, Inc.	26-1224181						
Pt I, Line 16:							
Description: Patient Registry Costs \$12,000							
Description: Research Grants \$40,745	,						
Description: Office Supplies \$1,953							
Description: Telephone \$1,792							
Description: Insurance \$1,650							
Description: Confrence, Convention, Meetings, & Tournaments \$42,704							
Description: Meals & Entertainment \$95							
Description: Travel \$22,732							
Description: Licences & Fees \$195							
Description: Fundraising Fees \$15							
Pt II, Line 24:							
Description: Charles Schwab Investment Account Beginning of Year: \$175,312 End of Year: \$184,519							
Pt II, Line 26:							
Description: Escrow for patient medical Beginning of Year: \$10,436 End of Year: \$8,707							
Description: Credit Card Payable Beginning of Year: \$648 End of Year: \$0							
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