2016

Open to Public

Inspection

60,402.

29.

60,402.

36,852

2,115.

36,536.

75,503.

<15,101.>

159,905.

144,804.

Form **990-EZ** (2016)

0.

917

18

19

20

21

Net Assets

Excess or (deficit) for the year (Subtract line 17 from line 9)

LHA For Paperwork Reduction Act Notice, see the separate instructions

Net assets or fund balances at beginning of year (from line 27, column (A))

Net assets or fund balances at end of year Combine lines 18 through 20

(must agree with end-of-year figure reported on prior year's return)

Other changes in net assets or fund balances (explain in Schedule 0)

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	m 990-EZ (2016) Hope for Hypothalamic Ham	nartomas		<u> 27-</u>	<u> 14334</u>	164	Page 2
Pa	art II Balance Sheets (see the instructions for Part II)						
	Check if the organization used Schedule O to res	spond to any ques		,			[]
	•		(A) Beginning of year	<u> </u>	(B) E	nd of yea	
22	Cash, savings, and investments	_	159,905	. 22		144,	804.
23	Land and buildings	L		23			
24	Other assets (describe in Schedule 0)			24			
25	Total assets		159,905	. 25		144,	804.
26	Total liabilities (describe in Schedule 0)		0.	. 26			0.
27	Net assets or fund balances (line 27 of column (B) must agree with line 21)		159,905	. 27		144,	804.
Pa	art III Statement of Program Service Accomplishmen	•	•		E	kpenses	
	Check if the organization used Schedule O to res	spond to any quest	tion in this Part III	X	(Required 501(c)(3)		
Wha	t is the organization's primary exempt purpose? See Schedule C)			organizati		
Desc	ribe the organization's program service accomplishments for each of its three largest program	services, as measured by expe	nses in a clear and concise	1	others)		
manr	ner, describe the services provided, the number of persons benefited, and other relevant inform	nation for each program title					
28	See Schedule O						
		·					
	(Grants \$) If this amount includes foreign g	rants, check here	>		28a	5,	213.
29	See Schedule O			[
				_ (
			·				
	(Grants \$) If this amount includes foreign of	grants, check here	▶ [29a	23,	605.
30	See Schedule O						
			1-1				
	(Grants \$) If this amount includes foreign g	rants, check here	▶ [30a	36,	852.
	Other program services (describe in Schedule O)	· · · -					
	(Grants \$) If this amount includes foreign of	rants, check here	▶ [31a		
				_			
32	Total program service expenses (add lines 28a through 31a)				32	65.	670.
	Total program service expenses (add lines 28a through 31a) art IV List of Officers, Directors, Trustees, and Key E	mployees (list each on	ne even if not compensated - s		32 nstructions f		<u>670.</u>
	art IV List of Officers, Directors, Trustees, and Key E						670.
	Total program service expenses (add lines 28a through 31a) Int IV List of Officers, Directors, Trustees, and Key E Check if the organization used Schedule O to res	pond to any quest	tion in this Part IV	ee the ir		or Part IV)	
	Check if the organization used Schedule O to res		(c) Reportable compensation (Forms	d) Heat	nstructions f		ımated
	art IV List of Officers, Directors, Trustees, and Key E	pond to any quest (b) Average hours	(c) Reportable compensation (Forms	d) Heat contrib employ	nstructions for	or Part IV)	imated of other
Pa	Check if the organization used Schedule O to res (a) Name and title	pond to any quest (b) Average hours per week devoted to	(c) Reportable compensation (Forms W-2/1099-MISC)	d) Heat contrib employ	nstructions for th benefits, outlons to see benefit and deferred	(e) Esti	imated of other
Pa	Check if the organization used Schedule O to res (a) Name and title ene Miller	pond to any quest (b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	d) Heat contrib employ	nstructions for th benefits, butions to see benefit and deferred ensation	(e) Esti	imated of other nsation
Pa Il Pr	Check if the organization used Schedule O to res (a) Name and title ene Miller esident	pond to any quest (b) Average hours per week devoted to	(c) Reportable compensation (Forms W-2/1099-MISC)	d) Heat contrib employ	nstructions for th benefits, outlons to see benefit and deferred	(e) Esti	imated of other
Pa Il Pr Li	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby	(b) Average hours per week devoted to position 35.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	d) Heat contrib employ	onstructions for the benefits, butions to ee benefit and deferred ensation	(e) Esti	imated of other asation
Il Pr Li Vi	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President	pond to any quest (b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	d) Heat contrib employ	nstructions for th benefits, butions to see benefit and deferred ensation	(e) Esti	imated of other nsation
Il Pr Li Vi Er	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster	(b) Average hours per week devoted to position 35.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	d) Heat contrib employ	th benefits, butions to ree benefit deferred ensation 0.	(e) Esti	imated of other isation 0.
Il Pr Li Vi Er Se	check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary	(b) Average hours per week devoted to position 35.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	d) Heat contrib employ	onstructions for the benefits, butions to ee benefit and deferred ensation	(e) Esti	imated of other asation
Il Pr Li Vi Er Se	check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane	(b) Average hours per week devoted to position 35.00 20.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	d) Heat contrib employ	th benefits, butions to see benefit addeferred ensation 0.	(e) Esti	ormated of other isation O.
Il Pr Li Vi Er Se Em	check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member	(b) Average hours per week devoted to position 35.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	d) Heat contrib employ	th benefits, butions to ree benefit deferred ensation 0.	(e) Esti	imated of other isation 0.
Pa Il Pr Li Vi Er Se Bo Ka	check if the organization used Schedule O to resched the organization used Schedule O to reschedule O to resch	(b) Average hours per week devoted to position 35.00 20.00 4.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit and deferred ensation O. O.	(e) Esti	ormated of other resation O.
Il Pr Li Vi Er Bo Ka Bo	check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ard Member ard Member	(b) Average hours per week devoted to position 35.00 20.00	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	d) Heat contrib employ	th benefits, butions to see benefit addeferred ensation 0.	(e) Esti	ormated of other isation O.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ard Member ard Member	(b) Average hours per week devoted to position 35.00 20.00 4.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit and deferred ensation O. O.	(e) Esti	ormated of other resation O.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.
Il Pr Li Er Em Bo Ka Bo We	Check if the organization used Schedule O to res (a) Name and title ene Miller esident sa Dunn Soeby ce President ica Webster cretary ma Kane ard Member thy Jensen ard Member ndi Tipps	(b) Average hours per week devoted to position 35.00 20.00 4.00 15.00	tion in this Part IV (c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-) 0. 0.	d) Heat contrib employ	th benefits, butions to see benefit deferred ensation 0. 0.	(e) Esti	omated of other resation 0.

12380214 726436 1261

1 1 2	of factors	
44a		X
44b		X
446		X
	1	
44d		
45a		X
45b		

Form 990-EZ (2016)

of Form 990-EZ

ın Schedule O

c Did the organization receive any payments for indoor tanning services during the year?

45a Did the organization have a controlled entity within the meaning of section 512(b)(13)?

d If "Yes" to line 44c, has the organization filed a Form 720 to report these payments? If "No," provide an explanation

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)

- TOTTI 990-EZ.//2	Hope for Hyp	otharamic ham	artomas			·	41-	14224	Yes	No
46 Bid the or	ganization engage, directly or indirectly	v in nolitical campaign activitie	s on behalf of or i	n oppositie	nn to cand	idates for ni	uhlic of	fice?	100	110
	omplete Schedule C, Part I	, in political campaign dooriso	o on bondir or or a	п орроопи				1	46	X
	Section 501(c)(3) organiza	tions only		······		···········				
	All section 501(c)(3) organizations		49b and 52, and	d complet	te the tab	les for line	s 50 a	nd 51.		
	Check if the organization used Sch									
									Yes	No
47 Did the or	ganization engage in lobbying activities	or have a section 501(h) elec	tion in effect durin	g the tax y	ear? If "Ye	s," complete	e Sch. (, Part II	47	X
	anization a school as described in secti								48	X
-	ganization make any transfers to an ex								19a	X
	as the related organization a section 52					 .		[4	19b	
50 Complete	this table for the organization's five hig	hest compensated employees	(other than officer	rs, director	rs, trustee:	s, and key e	mploye	es) who ea	ch received	1 more
than \$100	,000 of compensation from the <u>organi</u>	zation. If there is none, enter "N	lone."							
	(a) Name and title of each em	oloyee	(b) Average		(c) R	eportable	(d) Hea	alth benefits, butions to	(e) Estir	
			per week dev			ation (Forms 099-MISC)	emplo	yee benefit and deferred	amount c	
		NONE	positioi	n 			com	pensation	compen	Sauon
			•							
				 						
			•							
							<u> </u>			 ,
	ber of other employees paid over \$100						L			
organizati	this table for the organization's five hig on. If there is none, enter "None." ame and business address of each ind	NONE) Type of s				ompensatio	

						, , ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,				
d Total num	ber of other independent contractors e	each receiving over \$100,000			>					
52 Did the or	ganization complete Schedule A? Note	: All section 501(c)(3) organiza	ations must attach	a						
completed	Schedule A						,.	▶ 🔯] Yes	No
Under penalties	of perjury, I declare that I have examin	ned this return, including accor	npanying schedul	es and stat	tements, a	nd to the be	st of m	y knowledg	e and beli	ef, it is
true, correct, an	d complete. Declaration of preparer (o	ther than officer) is based on a	ll information of w	hich prepa	arer has ar	y knowledg	ie.			
	KCR							05/	13/2	20
Sign Here	Kimberly Ranson, Type or print name and title	Treasurer					Date			
		Dronararia ajanatura		Data	····	Check] ıf	PTIN		
	Print/Type preparer's name	Preparer's signature		Date		self- emplo	→ ''	F 61%		
Paid	73 X-55	B4 3 X- 5	£	02/1	4/20	agu- guipiu	yeu	בחחם	E0219)
Preparer	Edward Neff	Edward Nef		02/1	4/2U	F: 5:-			<u>59218</u>	<u> </u>
Use Only	Firm's name Taksey Ne				 	 		$\frac{6-236}{01 \cdot 20}$		30
	Firm's address ► 2 Resear Rockvill		e 210			Phone no	. (3	01)29	4-11(<i>,</i> 0
May the IDS die	ROCKV11J		· · · · · · · · · · · · · · · · · · ·	··· -· · · · · · · · · · · · · · · · ·		 		▶ 🗓	Tves [Nn

SCHEDULE A

Department of the Treasury

Internal Revenue Service

(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.

Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2016

Open to Public Inspection

Name of the organization Employer identification number Hope for Hypothalamic Hamartomas 27-1433464 Reason for Public Charity Status (All organizations must complete this part) See instructions Part I The organization is not a private foundation because it is (For lines 1 through 12, check only one box) A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). 1 2 A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990 or 990-EZ)) A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). 3 A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II) A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v). [X]An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II) A community trust described in section 170(b)(1)(A)(vi). (Complete Part II) 8 An agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions) Enter the name, city, and state of the college or university 10 An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See section 509(a)(2). (Complete Part III) An organization organized and operated exclusively to test for public safety. See section 509(a)(4). An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2) See section 509(a)(3). Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization You must complete Part IV, Sections A and B. Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s) You must complete Part IV, Sections A and C. Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions) You must complete Part IV, Sections A, D, and E. Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions) You must complete Part IV, Sections A and D, and Part V. Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization f Enter the number of supported organizations Provide the following information about the supported organization(s) (iv) is the organization listed in your governing document? (i) Name of supported (ii) EIN (III) Type of organization (v) Amount of monetary (vi) Amount of other (described on lines 1-10 organization support (see instructions) support (see instructions) No above (see instructions))

Schedule A (Form 990 or 990 EZ) 2016 Hope for Hypothalamic Hamartomas 27-1433464 Page 2

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

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

Se	ction A. Public Support						<u>,</u>
_	indar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
	Gifts, grants, contributions, and	\-7					
•	membership fees received (Do not					i	
	include any "unusual grants ")	35,511.	31,431.	55,242.	70,929.	60,373.	253,486.
2	Tax revenues levied for the organ-						
	ization's benefit and either paid to						
	or expended on its behalf						
3	The value of services or facilities						
	furnished by a governmental unit to		İ				
	the organization without charge						
4	Total. Add lines 1 through 3	35,511.	31,431.	55,242.	70,929.	60,373.	253,486.
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		İ				
	amount shown on line 11,						
	column (f)			,			133,593.
6	Public support. Subtract line 5 from line 4						119,893.
	ction B. Total Support						
Cale	ndar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
7	Amounts from line 4	35,511.	31,431.	55,242.	70,929.	60,373.	253,486.
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties						
	and income from similar sources	8.	9.	17.	21.	29.	84.
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						253,570.
12	Gross receipts from related activities,	etc (see instruction	ons)			12	
	First five years. If the Form 990 is for			, fourth, or fifth ta	k year as a section	n 501(c)(3)	
	organization, check this box and stop						▶ □
Sec	ction C. Computation of Publi	c Support Per	centage				
14	Public support percentage for 2016 (li	ne 6, column (f) di	vided by line 11, co	olumn (f))		14	47.28 %
15	Public support percentage from 2015	Schedule A, Part	II, line 14			15	51.25 %
16a	33 1/3% support test - 2016. If the o	rganization did no	t check the box on	line 13, and line 1	4 is 33 1/3% or m	nore, check this bo	x and
	stop here. The organization qualifies a	as a publicly suppo	orted organization				▶ X
b	33 1/3% support test - 2015. If the o			ne 13 or 16a, and I	line 15 is 33 1/3%	or more, check th	is box
	and stop here. The organization qualit	fies as a publicly s	upported organiza	tion			▶□
17a	10% -facts-and-circumstances test	- 2016. If the orga	anization did not ch	neck a box on line	13, 16a, or 16b, a	and line 14 is 10%	or more,
	and if the organization meets the "fact	_					
	meets the "facts and-circumstances" t			•		,	ightharpoons
b	10% -facts-and-circumstances test					7a, and line 15 is	10% or
	more, and if the organization meets th						
	organization meets the "facts-and-circ						ightharpoons
18	Private foundation. If the organization						▶ □
					0.1	1 1 4 /F	000 57) 0040

Schedule A (Form 990 or 990-EZ) 2016

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

qualify under the tests listed be section A. Public Support	iow, piease com	piete Part II)				
alendar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants")						
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						
Tax revenues levied for the organ- ization's benefit and either paid to or expended on its behalf					/	
The value of services or facilities furnished by a governmental unit to the organization without charge						
5 Total. Add lines 1 through 5						
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 or 1% of the amount on line 13 for the year	7.00 (.7.50					
c Add lines 7a and 7b					1	
B Public support. (Subtract line 7c from line 6.)						
ection B. Total Support		1			•	•
lendar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
Amounts from line 6			/			
da Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses						
acquired after June 30, 1975			ļ		<u> </u>	
c Add lines 10a and 10b Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on	/					
2 Other income Do not include gain or loss from the sale of capital assets (Explain in Part VI)						
Total support (Add lines 9, 10c, 11, and 12)	/	l				<u></u>
First five years. If the Form 990 is for t	he organization':	s first, second, thi	rd, fourth, or fifth t	ax year as a section	on 501(c)(3) organ	ızatıon,
check this box and stop here	/			· · · · · · · · · · · · · · · · · · ·		<u>▶</u> _
ction C. Computation of Public						
Public support percentage for 2016 (lin		-	column (f))		15	
Public support percentage from 2015 S					16	
ction D. Computation of Invest	ment Incom	e Percentage	<u> </u>			
Investment income percentage for 201	6 (line 10c, colur	nn (f) divided by li	ne 13, column (f))		17	
Investment income percentage from 20	15 Schedule A,	Part III, line 17			18	
a 33 1/3% support tests - 2016. If the o	rganization did r	not check the box	on line 14, and lin	e 15 is more than :	33 1/3%, and line	17 is not
more than 33 1/3%, check this box and b 33 1/3% support tests - 2015. If the o	-					▶ [
line 18 is not more than 33 1/3%, chec	-					
Private foundation. If the organization			•		-	▶ □
2023 09-21-16					edule A (Form 99	200 57) 04

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
- 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
- 5a 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?
- Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI.
- 7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ)
- 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 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)

		Yes	No
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	3b		
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	5b		
	5c		<u> </u>
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	7		
	8		
	9a		
	- 9b		
	35		
,	9c		
	10a		
	10b		
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Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see

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6

Distributable Amount. Subtract line 5 from line 4, unless subject to

emergency temporary reduction (see instructions)

instructions)

Schedule A (Form 990 or 990-EZ) 2016

а

b Excess from 2013c Excess from 2014d Excess from 2015e Excess from 2016

Part VI	(Form 990 or 990-EZ) 2016 HODE FOR HYPOTRALAMIC HAMARTOMAS 27-1433464 Page of Supplemental Information. Provide the explanations required by Part II, line 10, Part II, line 17a or 17b, Part III, line 12, Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c, Part IV, Section B, lines 1 and 2, Part IV, Section C, line 1, Part IV, Section D, lines 2 and 3, Part IV, Section E, lines 1c, 2a, 2b, 3a, and 3b, Part V, line 1, Part V, Section B, line 1e, Part V, Section D, lines 5, 6, and 8, and Part V, Section E, lines 2, 5, and 6 Also complete this part for any additional information (See instructions)
<u> </u>	
	
	

SCHEDULE O

(Form 990 or 990-EZ)

Department of the Treasury

Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

➤ Attach to Form 990 or 990-EZ.

OMB No 1545-0047

Open to Public Inspection

Name of the organization

Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990. Employer identification number 27-1433464 Hope for Hypothalamic Hamartomas Form 990-EZ, Part I, Line 4, Other Investment Income: Amount: Description of Property: 29. Investment Interest Form 990-EZ, Part I, Line 10, Grants and Allocations: Activity Classification: Research Grantee Name: Wilcox-West Date of Gift: 03/29/17 Amount Given: 10,000. Activity Classification: Research Grantee Name: Boerwinkle Date of Gift: 03/06/17 Amount Given: 26,852. Total included on Form 990-EZ, line 10 36,852. Form 990-EZ, Part I, Line 16, Other Expenses: Description of Other Expenses: Amount: Digital & web 2,610. 127. 1,114.

Patient aid surgical gift bags LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule O (Form 990 or 990-EZ) (2016)

1,865.

10.

153.

2,870.

Memberships

Insurance

Database

Supplies

Filing fee

SCHEDULE 0 (Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

► Attach to Form 990 or 990-EZ. Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990. OMB No 1545-0047 Open to Public Inspection

Name of the organization

Hope for Hypothalamic Hamartomas

Employer identification number 27-1433464

Hope for Hypothalamic Hamartomas	27-1433464
Professional conferences	25,947.
Medical advisory board hotel	1,840.
Total to Form 990-EZ, line 16	36,536.
	And the second s
Form 990-EZ, Part III, Primary Exempt Purpose - Hope for	Hypothalamic
Hamartomas provides information, support and community to	HH patients,
caregivers and healthcare providers. We promote research	into early
detection, improved treatments, living with HH as a comple	ex medical
syndrome, and cure.	
Form 990-EZ, Part III, Line 28, Program Service Accomplish	hments:
Receiving a diagnosis of Hypothalamic Hamartoma (HH) can	
be overwhelming and may leave a patient and their	
caregivers with many unanswered questions and feelings of	
isolation. Hope for HH organizes a biennial Family Forum	designed to
bring together disparate patients and caregivers from arou	und the globe
for information, networking, and community. Hope for HH is	nvites the
foremost HH experts to present the most up-to-date research	ch on
treatments, comorbidities, best care practices and daily	living
challenges. Given the rarity of the disease and how disper	rsed families
are, for many patients, this is the only time they will me	eet another HH
patient and caregiver. Hope for HH also awards financial	aid for travel
to the Family Forum to ensure wide-spread access. Moreover	r, key Family
Forum information sessions are videorecorded so the content	nt can be
broadly disseminated post conference to serve an internat:	ional
audience. In addition to Family Forums, Hope for HH staffs LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Sched	s Information ule O (Form 990 or 990-EZ) (2016)

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. ► Attach to Form 990 or 990-EZ.

Open to Public

OMB No 1545-0047

Inspection

Department of the Treasury Internal Revenue Service Name of the organization

▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs gov/form990.

Hope for Hypothalamic Hamartomas

Employer identification number 27-1433464

and Referral service to answer questions, provide referrals, and offer support to newly diagnosed patients as well as those living with and managing the disease over the course of their lifetime. Moreover, Hope for HH maintains an in-depth website, weekly blog, monthly electronic newsletter, daily social media channels, and downloadable print materials on many topics from Questions to ask a Neurosurgeon through to A Seizure Action plan - all to ensure the widespread availability of information and support for patients and their families. Patients preparing for surgery at two of the centers with the largest volume of surgical patients will also receive a Comfort Care bag filled with

Form 990-EZ, Part III, Line 29, Program Service Accomplishments: Hope for HH coordinates a triennial International Research Symposium to provide an opportunity for otherwise disparately located HH experts, researchers and clinicians to exchange information, share best practices, identify gaps, seed collaborations and develop a roadmap to improve diagnosis, treatment, management, and cure. The inaugural meeting was in Marseille, France in 2013 and has been convened every 3 years since including London (2016) and Washington DC (2019). The meeting began with 35 HH experts and has grown to include more than 60 HH experts and epilepsy thought leaders across 11 countries, 25 institutions and many subspecialties including neurosurgery, neurology, endocrinology, radiology, neuropsychiatry, neuropsychology, genetics, basic research, and epidemiology.

comfort items for the patients and caregivers.

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.

▶ Attach to Form 990 or 990-EZ. ▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990. OMB No 1545-0047 Open to Public Inspection

Name of the organization

Department of the Treasury

Internal Revenue Service

Hope for Hypothalamic Hamartomas

Employer identification number 27-1433464

Form 990-EZ, Part III, Line 30, Program Service Accomplishments:
Hope for HH funds research for better treatments and a
cure for Hypothalamic Hamartoma syndrome, comorbidities
and related epilepsies by awarding research grants to
qualified scientists and clinicians. Hope for HH also awards grants to
support the professional development, training and mentoring of Young
Investigators. Hope for HH grants fund basic, clinical, and
translational science. The results extracted from this research will
seed larger scale multi-institutional international collaborations and
enable promising projects to qualify for larger governmental and other
funding sources. Research areas include developing FMRI for surgical
planning to improve targeting and outcomes, developing animal model for
HH, exome sequencing and genetics, comparative effective surgery pilot,
Young Investigator development, Symposium and conference support, and
SUDEP research.
Form 990-EZ, Part V, Information Regarding Personal Benefit Contracts:
Form 990-EZ, Part V, Information Regarding Personal Benefit Contracts: The organization did not, during the year, receive any funds, directly,
The organization did not, during the year, receive any funds, directly,
The organization did not, during the year, receive any funds, directly, or indirectly, to pay premiums on a personal benefit contract.
The organization did not, during the year, receive any funds, directly, or indirectly, to pay premiums on a personal benefit contract. The organization, did not, during the year, pay any premiums, directly,
The organization did not, during the year, receive any funds, directly, or indirectly, to pay premiums on a personal benefit contract. The organization, did not, during the year, pay any premiums, directly,

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule O (Form 990 or 990-EZ) (2016)