

Form **990**

Return of Organization Exempt From Income Tax
Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

OMB No. 1545-0047

2013

Department of the Treasury
Internal Revenue Service

Do not enter Social Security numbers on this form as it may be made public.

Information about Form 990 and its instructions is at www.irs.gov/form990

Open to Public Inspection

A For the 2013 calendar year, or tax year beginning JUL 1, 2013 and ending JUN 30, 2014

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization		D Employer identification number	
	FAMILIES OF SPINAL MUSCULAR ATROPHY		36-3320440	
	Doing Business As CURE SMA			
	Number and street (or P.O. box if mail is not delivered to street address) Room/suite		E Telephone number	
925 BUSSE ROAD		800-886-1762		
City or town, state or province, country, and ZIP or foreign postal code		G Gross receipts \$		
ELK GROVE VILLAGE, IL 60007		5,227,297.		
F Name and address of principal officer: KENNETH HOBBY		H(a) Is this a group return		
SAME AS C ABOVE		for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
		H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No		
		If "No," attach a list. (see instructions)		
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		H(c) Group exemption number ▶		
J Website: WWW.CURESMA.ORG				
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶		L Year of formation: 1984 M State of legal domicile: IL		

Part I Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: <u>SEE SCHEDULE O</u>	
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.	
	3	Number of voting members of the governing body (Part VI, line 1a) 15
	4	Number of independent voting members of the governing body (Part VI, line 1b) 14
	5	Total number of individuals employed in calendar year 2013 (Part V, line 2a) 18
	6	Total number of volunteers (estimate if necessary) 5000
	7a	Total unrelated business revenue from Part VIII, column (C), line 12 122.
	7b	Net unrelated business taxable income from Form 990-T, line 34 0.
Revenue	8	Contributions and grants (Part VIII, line 1h) 4,596,877. 4,639,671.
	9	Program service revenue (Part VIII, line 2g) 324,212. 381,031.
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d) 13,901. 3,452.
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) -2,662. 26,540.
	12	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) 4,932,328. 5,050,694.
Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1-3) 1,232,668. 1,004,654.
	14	Benefits paid to or for members (Part IX, column (A), line 4) 0. 0.
	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) 1,137,972. 1,355,302.
	16a	Professional fundraising fees (Part IX, column (A), line 11e) 0. 15,413.
	16b	Total fundraising expenses (Part IX, column (D), line 25) ▶ 1,361,698.
	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) 2,137,256. 2,460,052.
	18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) 4,507,896. 4,835,421.
19	Revenue less expenses. Subtract line 18 from line 12 424,432. 215,273.	
Net Assets or Fund Balances	20	Total assets (Part X, line 16) 3,439,299. 3,380,394.
	21	Total liabilities (Part X, line 26) 1,394,203. 1,155,939.
	22	Net assets or fund balances. Subtract line 21 from line 20 2,045,096. 2,224,455.

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here	Signature of officer		Date		
	KENNETH HOBBY, PRESIDENT				
Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check <input type="checkbox"/> if self-employed	PTIN
	GEOFFREY ADAMS		11/12/14		P00541065
	Firm's name ▶ KAUFMAN, ROSSIN & CO., P.A.	Firm's EIN ▶ 59-1818353		Phone no. 305-858-5600	
Firm's address ▶ 2699 S. BAYSHORE DRIVE		MIAMI, FL 33133			

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III [X]

1 Briefly describe the organization's mission: FAMILIES OF SPINAL MUSCULAR ATROPHY (D/B/A CURE SMA) FUNDS AND DIRECTS THE LEADING SMA RESEARCH PROGRAMS TO DEVELOP A TREATMENT AND CURE FOR THE DISEASE. THE SUCCESSFUL RESULTS AND PROGRESS THAT THE ORGANIZATION HAS DELIVERED, FROM BASIC RESEARCH TO DRUG DISCOVERY TO

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [] Yes [X] No

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [] Yes [X] No

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 1,273,503. including grants of \$) (Revenue \$ 17,770.) CURE SMA PROVIDES INVALUABLE SUPPORT AND SERVICES TO INDIVIDUALS AND FAMILIES SUCH AS MEDICAL INFORMATION, EQUIPMENT, FAMILY SUPPORT AND RESOURCES. LOCAL COMMUNITY SUPPORT IS AVAILABLE THROUGH OUR VAST VOLUNTEER NETWORK. FOR NEWLY DIAGNOSED FAMILIES WE PROVIDE EMOTIONAL SUPPORT AND WILL PROVIDE A COMPREHENSIVE INFORMATIONAL PACKET AS WELL AS A "CARE PACKAGE" OF TOYS FOR EACH CHILD, SPECIFIC TO THE DISEASE TYPE. CURE SMA HAS COMPREHENSIVE INFORMATION AVAILABLE ON CRITICAL TOPICS ON SMA MEDICAL CARE INCLUDING GENETICS, RESPIRATORY CARE, NUTRITION AND MUCH MORE. OUR MEMBERS ARE PROVIDED A SUBSCRIPTION TO OUR FAMILY SUPPORT NEWSLETTER CALLED DIRECTIONS THAT IS DEDICATED TO NEWS AND PROGRESS. COMPASS NEWSLETTER FOCUSES ON RESEARCH UPDATES, HIGHLIGHTING ALL MAJOR RESEARCH DEVELOPMENTS. WE OFFER SUPPORT

4b (Code:) (Expenses \$ 1,375,175. including grants of \$ 1,004,654.) (Revenue \$) CURE SMA HAS FUNDED NEARLY TWO THIRDS OF ALL THE ONGOING DRUG PROGRAMS FOR SMA. IN THE PAST 18 MONTHS, CURE SMA HAS FUNDED FIVE ADDITIONAL NEW DRUG PROGRAMS, INCLUDING THE FOLLOWING IN JUST THE PAST FEW MONTHS: ASSESSING SECOND-GENERATION ASO SEQUENCES FOR SMA; USING A PATIENT DERIVED MOTOR NEURON SCREEN TO IDENTIFY NOVEL SMA THERAPEUTICS; AND TESTING IN SMA MICE A DRUG THAT ENHANCES MUSCLE FUNCTION NOW IN PHASE II TRIALS FOR ALS.

DEVELOPING NEW THERAPIES TO TREAT AND ULTIMATELY CURE SMA IS THE DRIVING FORCE BEHIND CURE SMA. TO ACHIEVE THIS GOAL, CURE SMA AGGRESSIVELY INVESTS IN BASIC RESEARCH TO IDENTIFY THERAPEUTIC APPROACHES AND THEN APPLIED DRUG DEVELOPMENT TO MAKE DRUGS. CURE SMA

4c (Code:) (Expenses \$ 575,251. including grants of \$) (Revenue \$ 381,031.) CURE SMA HOSTED ITS 25TH ANNUAL NATIONAL CONFERENCE IN WASHINGTON DC. OVER 1350 FAMILIES AND MEMBERS OF THE SCIENTIFIC COMMUNITY FROM 23 COUNTRIES AROUND THE WORLD PARTICIPATED. THE CONFERENCE PROVIDES NETWORKING OPPORTUNITIES WITH OTHER FAMILIES, WORKSHOPS AND MEMORABLE CHILDREN'S PROGRAMING. IT IS THE GOAL OF CURE SMA TO PROVIDE THE FAMILIES WITH THE OPPORTUNITY TO INTERACT WITH RESEARCHERS AND MEDICAL PROVIDERS TO SHARE IDEAS AND HOPE FOR THE FUTURE.

4d Other program services (Describe in Schedule O.) (Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 3,223,929.

Part IV Checklist of Required Schedules

		Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	X	
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ?	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		X
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>	X	
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III</i>		X
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i>		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>		X
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>	X	
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i>	X	
b	Did the organization report an amount for investments - other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i>		X
c	Did the organization report an amount for investments - program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i>		X
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>		X
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>		X
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>	X	
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	X	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?		X
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i>		X
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>		X
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>		X
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i>	X	
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>	X	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		X
20a	Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		X
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		

Part IV Checklist of Required Schedules (continued)

		Yes	No
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	X	
22	Did the organization report more than \$5,000 of grants or other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>		X
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	X	
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		X
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
24b			
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
24c			
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
24d			
25a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>		X
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>		X
25b			X
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? If so, complete Schedule L, Part II		X
26			X
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>		X
27			X
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
a	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
28a			X
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
28b			X
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>		X
28c			X
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	X	
29		X	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>		X
30			X
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		X
31			X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>		X
32			X
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>		X
33			X
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>		X
34			X
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
35a			X
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>		
35b			
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		X
36			X
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>		X
37			X
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	X	
38		X	

Note. All Form 990 filers are required to complete Schedule O

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Main form area containing questions 1a through 14b with input fields and Yes/No columns.

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

Check if Schedule O contains a response or note to any line in this Part VI [X]

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a (15), 1b (14), 2, 3, 4, 5, 6, 7a, 7b, 8a, 8b, 9.

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

Table with 3 columns: Question, Yes, No. Rows include: 10a, 10b, 11a, 11b, 12a, 12b, 12c, 13, 14, 15a, 15b, 16a, 16b.

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed AL, AZ, CA, CO, CT, FL, IA, IL, KS, LA, MA, MI
18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection.
19 Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization: KENNETH HOBBY - 800-886-1762, 925 BUSSE ROAD, ELK GROVE VILLAGE, IL 60007

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

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

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) RICHARD RUBENSTEIN BOARD CHAIR	6.00	X		X				0.	0.	0.
(2) KENNETH HOBBY PRESIDENT	70.00	X		X			145,167.	0.	8,229.	
(3) STEVE RAGLAND SECRETARY	6.00	X		X			0.	0.	0.	
(4) BRAD NUNEMAKER TREASURER	6.00	X		X			0.	0.	0.	
(5) ADI RAPPOPORT DIRECTOR	2.00	X					0.	0.	0.	
(6) NATALIE GIBBS DIRECTOR	2.00	X					0.	0.	0.	
(7) ROCCO ARIZZI DIRECTOR	4.00	X					0.	0.	0.	
(8) MARY MCHALE DIRECTOR	2.00	X					0.	0.	0.	
(9) DOUGLAS ERWIN DIRECTOR	2.00	X					0.	0.	0.	
(10) ROBERT LOCKWOOD DIRECTOR	2.00	X					0.	0.	0.	
(11) MELISSA MILINOVICH DIRECTOR	2.00	X					0.	0.	0.	
(12) JUSTIN KUESTER DIRECTOR	2.00	X					0.	0.	0.	
(13) BARB TRAINOR DIRECTOR	2.50	X					0.	0.	0.	
(14) COREY BRAASTAD DIRECTOR	2.00	X					0.	0.	0.	
(15) GREG ZERZAN DIRECTOR	2.00	X					0.	0.	0.	
(16) JILL JARECKI RESEARCH DIRECTOR	70.00				X		125,745.	0.	84.	
(17) THEODORE WACHHOLZ OPERATIONS/FINANCE DIRECTO	50.00				X		116,230.	0.	6,356.	

Part VIII Statement of Revenue

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

		(A)	(B)	(C)	(D)	
		Total revenue	Related or exempt function revenue	Unrelated business revenue	Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants and Other Similar Amounts	1 a Federated campaigns	1a				
	b Membership dues	1b				
	c Fundraising events	1c 3,000,759.				
	d Related organizations	1d				
	e Government grants (contributions)	1e 28,000.				
	f All other contributions, gifts, grants, and similar amounts not included above	1f 1,610,912.				
	g Noncash contributions included in lines 1a-1f: \$	105,099.				
	h Total. Add lines 1a-1f	▶ 4,639,671.				
	Program Service Revenue	2 a ANNUAL CONFERENCE	Business Code 900099	381,031.	381,031.	
b						
c						
d						
e						
f All other program service revenue						
g Total. Add lines 2a-2f		▶ 381,031.				
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)	▶	3,330.		3,330.	
	4 Income from investment of tax-exempt bond proceeds	▶				
	5 Royalties	▶				
	6 a Gross rents	(i) Real				
		(ii) Personal				
		b Less: rental expenses				
		c Rental income or (loss)				
	d Net rental income or (loss)	▶				
	7 a Gross amount from sales of assets other than inventory	(i) Securities	10,096.			
		(ii) Other				
		b Less: cost or other basis and sales expenses	9,974.			
		c Gain or (loss)	122.			
	d Net gain or (loss)	▶	122.		122.	
	8 a Gross income from fundraising events (not including \$ 3,000,759. of contributions reported on line 1c). See Part IV, line 18	a	175,399.			
		b Less: direct expenses	b 166,629.			
c Net income or (loss) from fundraising events		▶	8,770.		8,770.	
9 a Gross income from gaming activities. See Part IV, line 19	a					
	b Less: direct expenses	b				
	c Net income or (loss) from gaming activities	▶				
10 a Gross sales of inventory, less returns and allowances	a					
	b Less: cost of goods sold	b				
	c Net income or (loss) from sales of inventory	▶				
Miscellaneous Revenue		Business Code				
11 a MISCELLANEOUS	900099	17,770.	17,770.			
	b					
	c					
	d All other revenue					
	e Total. Add lines 11a-11d	▶	17,770.			
12 Total revenue. See instructions.	▶	5,050,694.	398,801.	122.	12,100.	

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the United States. See Part IV, line 21	1,004,654.	1,004,654.		
2 Grants and other assistance to individuals in the United States. See Part IV, line 22				
3 Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	156,514.	104,343.	26,086.	26,085.
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	1,067,752.	651,507.	83,053.	333,192.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	45,387.	30,222.	196.	14,969.
10 Payroll taxes	85,649.	51,084.	8,264.	26,301.
11 Fees for services (non-employees):				
a Management				
b Legal	31,844.	15,804.	250.	15,790.
c Accounting	36,362.	22,908.	7,727.	5,727.
d Lobbying	49,530.	48,241.	1,289.	
e Professional fundraising services. See Part IV, line 17	15,413.			15,413.
f Investment management fees				
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)	254,381.	99,250.	41,685.	113,446.
12 Advertising and promotion	57,920.	38,690.	9,611.	9,619.
13 Office expenses	284,826.	176,934.	18,143.	89,749.
14 Information technology	132,542.	78,936.	6,400.	47,206.
15 Royalties				
16 Occupancy	86,303.	56,988.	14,267.	15,048.
17 Travel	99,614.	27,295.	17,671.	54,648.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	577,334.	575,251.	343.	1,740.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	39,846.	35,220.	2,313.	2,313.
23 Insurance	15,114.	10,076.	2,519.	2,519.
24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a FUNDRAISING EVENTS	647,954.	89,196.	3,099.	555,659.
b PATIENT SERVICES	111,143.	103,973.		7,170.
c MERCHANDISE	23,076.			23,076.
d MISCELLANEOUS	12,263.	3,357.	6,878.	2,028.
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	4,835,421.	3,223,929.	249,794.	1,361,698.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Check here if following SOP 98-2 (ASC 958-720)

Part X Balance Sheet

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

		(A) Beginning of year		(B) End of year		
Assets	1 Cash - non-interest-bearing	2,644,145.	1	2,400,803.		
	2 Savings and temporary cash investments	411,463.	2	337,411.		
	3 Pledges and grants receivable, net	149,349.	3	279,648.		
	4 Accounts receivable, net	55,490.	4	99,413.		
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5			
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instr). Complete Part II of Sch L		6			
	7 Notes and loans receivable, net		7			
	8 Inventories for sale or use		8			
	9 Prepaid expenses and deferred charges		9			
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 586,395.				
	b Less: accumulated depreciation	10b 329,620.	136,594.	10c	256,775.	
	11 Investments - publicly traded securities			11		
	12 Investments - other securities. See Part IV, line 11	36,461.		12	547.	
	13 Investments - program-related. See Part IV, line 11			13		
	14 Intangible assets			14		
	15 Other assets. See Part IV, line 11	5,797.		15	5,797.	
16 Total assets. Add lines 1 through 15 (must equal line 34)	3,439,299.		16	3,380,394.		
Liabilities	17 Accounts payable and accrued expenses	389,641.	17	469,441.		
	18 Grants payable	1,004,562.	18	686,498.		
	19 Deferred revenue		19			
	20 Tax-exempt bond liabilities		20			
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21			
	22 Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		22			
	23 Secured mortgages and notes payable to unrelated third parties		23			
	24 Unsecured notes and loans payable to unrelated third parties		24			
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D		25			
	26 Total liabilities. Add lines 17 through 25	1,394,203.	26		1,155,939.	
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.					
	27 Unrestricted net assets	1,104,164.	27	1,275,179.		
	28 Temporarily restricted net assets	533,986.	28	358,761.		
	29 Permanently restricted net assets	406,946.	29	590,515.		
	Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.					
	30 Capital stock or trust principal, or current funds		30			
	31 Paid-in or capital surplus, or land, building, or equipment fund		31			
	32 Retained earnings, endowment, accumulated income, or other funds		32			
33 Total net assets or fund balances	2,045,096.	33		2,224,455.		
34 Total liabilities and net assets/fund balances	3,439,299.	34		3,380,394.		

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	5,050,694.
2	Total expenses (must equal Part IX, column (A), line 25)	2	4,835,421.
3	Revenue less expenses. Subtract line 2 from line 1	3	215,273.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	2,045,096.
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	-35,914.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	2,224,455.

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other		
If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		X
If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:			
<input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis			
2b	Were the organization's financial statements audited by an independent accountant?	X	
If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:			
<input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis			
2c	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?	X	
If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.			
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		X
3b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits		

Form 990 (2013)

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

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

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	3,553,474.	3,603,995.	4,241,909.	4,596,877.	4,639,671.	20,635,926.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	3,553,474.	3,603,995.	4,241,909.	4,596,877.	4,639,671.	20,635,926.
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.						20,635,926.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7 Amounts from line 4	3,553,474.	3,603,995.	4,241,909.	4,596,877.	4,639,671.	20,635,926.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	2,892.	1,278.	2,193.	2,391.	3,330.	12,084.
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 IV.)	949,490.	918,280.	362,448.	589,565.	556,430.	3,376,213.
11 Total support. Add lines 7 through 10						24,024,223.
12 Gross receipts from related activities, etc. (see instructions)					12	2,769,908.
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here	<input type="checkbox"/>					

Section C. Computation of Public Support Percentage

14 Public support percentage for 2013 (line 6, column (f) divided by line 11, column (f))	14	85.90 %
15 Public support percentage from 2012 Schedule A, Part II, line 14	15	85.54 %
16a 33 1/3% support test - 2013. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	<input checked="" type="checkbox"/>	
b 33 1/3% support test - 2012. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
17a 10% -facts-and-circumstances test - 2013. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
b 10% -facts-and-circumstances test - 2012. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions	<input type="checkbox"/>	

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

(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 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						
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						
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						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
9 Amounts from line 6						
10a 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						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**

Section C. Computation of Public Support Percentage

15 Public support percentage for 2013 (line 8, column (f) divided by line 13, column (f))	15	%
16 Public support percentage from 2012 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2013 (line 10c, column (f) divided by line 13, column (f))	17	%
18 Investment income percentage from 2012 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2013. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization

b 33 1/3% support tests - 2012. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

Schedule B
(Form 990, 990-EZ,
or 990-PF)

Department of the Treasury
Internal Revenue Service

Schedule of Contributors

▶ Attach to Form 990, Form 990-EZ, or Form 990-PF.
▶ Information about Schedule B (Form 990, 990-EZ, or 990-PF) and
its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2013

Name of the organization

Employer identification number

FAMILIES OF SPINAL MUSCULAR ATROPHY

36-3320440

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

501(c)(3) (enter number) organization

4947(a)(1) nonexempt charitable trust **not** treated as a private foundation

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

4947(a)(1) nonexempt charitable trust treated as a private foundation

501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**.

Note. Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II.

Special Rules

For a section 501(c)(3) organization filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi) and received from any one contributor, during the year, a contribution of the greater of (1) \$5,000 or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h, or (ii) Form 990-EZ, line 1. Complete Parts I and II.

For a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 for use *exclusively* for religious, charitable, scientific, literary, or educational purposes, or the prevention of cruelty to children or animals. Complete Parts I, II, and III.

For a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions for use *exclusively* for religious, charitable, etc., purposes, but these contributions did not total to more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Do not complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions of \$5,000 or more during the year ▶ \$ _____

Caution. An organization that is not covered by the General Rule and/or the Special Rules does not file Schedule B (Form 990, 990-EZ, or 990-PF), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it does not meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990, 990-EZ, or 990-PF. Schedule B (Form 990, 990-EZ, or 990-PF) (2013)

Name of organization FAMILIES OF SPINAL MUSCULAR ATROPHY	Employer identification number 36-3320440
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Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	<hr/> <hr/> <hr/> <hr/>	\$ <u>100,000.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization FAMILIES OF SPINAL MUSCULAR ATROPHY	Employer identification number 36-3320440
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Part II Noncash Property (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		\$ _____	
		\$ _____	
		\$ _____	
		\$ _____	
		\$ _____	
		\$ _____	
		\$ _____	
		\$ _____	
		\$ _____	

Name of organization FAMILIES OF SPINAL MUSCULAR ATROPHY	Employer identification number 36-3320440
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Part III Exclusively religious, charitable, etc., individual contributions to section 501(c)(7), (8), or (10) organizations that total more than \$1,000 for the year. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this information once.) ▶ \$ _____
Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
_____	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
_____		_____	
_____	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
_____		_____	
_____	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
_____		_____	
_____	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
_____		_____	
_____	_____	_____	_____
	_____	_____	_____
	_____	_____	_____

SCHEDULE C
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under section 501(c) and section 527

▶ **Complete if the organization is described below.** ▶ **Attach to Form 990 or Form 990-EZ.**
▶ **See separate instructions.** ▶ **Information about Schedule C (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.**

OMB No. 1545-0047

2013

Open to Public Inspection

If the organization answered "Yes," to Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations: Complete Parts I-A and B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes," to Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

If the organization answered "Yes," to Form 990, Part IV, line 5 (Proxy Tax) or Form 990-EZ, Part V, line 35c (Proxy Tax), then

- Section 501(c)(4), (5), or (6) organizations: Complete Part III.

Name of organization FAMILIES OF SPINAL MUSCULAR ATROPHY	Employer identification number 36-3320440
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Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV.
- 2 Political expenditures ▶ \$ _____
- 3 Volunteer hours _____

Part I-B Complete if the organization is exempt under section 501(c)(3).

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 ▶ \$ _____
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ \$ _____
- 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? Yes No
- 4a Was a correction made? Yes No
- b If "Yes," describe in Part IV.

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ▶ \$ _____
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ▶ \$ _____
- 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b ▶ \$ _____
- 4 Did the filing organization file **Form 1120-POL** for this year? Yes No
- 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV.

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds. If none, enter -0-.	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-.

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule C (Form 990 or 990-EZ) 2013

Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

- A** Check if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).
- B** Check if the filing organization checked box A and "limited control" provisions apply.

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
1 a	Total lobbying expenditures to influence public opinion (grass roots lobbying)														
b	Total lobbying expenditures to influence a legislative body (direct lobbying)														
c	Total lobbying expenditures (add lines 1a and 1b)														
d	Other exempt purpose expenditures														
e	Total exempt purpose expenditures (add lines 1c and 1d)														
f	Lobbying nontaxable amount. Enter the amount from the following table in both columns.														
<table border="1" style="width: 100%;"> <thead> <tr> <th style="text-align: left;">If the amount on line 1e, column (a) or (b) is:</th> <th style="text-align: left;">The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table>		If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	Not over \$500,000	20% of the amount on line 1e.	Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.	Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.	Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.	Over \$17,000,000	\$1,000,000.		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:														
Not over \$500,000	20% of the amount on line 1e.														
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.														
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.														
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.														
Over \$17,000,000	\$1,000,000.														
g	Grassroots nontaxable amount (enter 25% of line 1f)														
h	Subtract line 1g from line 1a. If zero or less, enter -0-														
i	Subtract line 1f from line 1c. If zero or less, enter -0-														
j	If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?		<input type="checkbox"/> Yes <input type="checkbox"/> No												

4-Year Averaging Period Under Section 501(h)
(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the instructions for lines 2a through 2f on page 4.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2010	(b) 2011	(c) 2012	(d) 2013	(e) Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column(e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes," response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.	(a)		(b)
	Yes	No	Amount
1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?		X	
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? ..		X	
c Media advertisements?		X	
d Mailings to members, legislators, or the public?		X	
e Publications, or published or broadcast statements?		X	
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?		X	
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		X	
i Other activities?	X		49,530.
j Total. Add lines 1c through 1i			49,530.
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		X	
b If "Yes," enter the amount of any tax incurred under section 4912			
c If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

	Yes	No
1 Were substantially all (90% or more) dues received nondeductible by members?	1	
2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	
3 Did the organization agree to carry over lobbying and political expenditures from the prior year?	3	

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No," OR (b) Part III-A, line 3, is answered "Yes."

1 Dues, assessments and similar amounts from members	1	
2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).		
a Current year	2a	
b Carryover from last year	2b	
c Total	2c	
3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	3	
4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?	4	
5 Taxable amount of lobbying and political expenditures (see instructions)	5	

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, line 2; and Part II-B, line 1. Also, complete this part for any additional information.

PART II-B, LINE 1, LOBBYING ACTIVITIES:

EXPLANATION: THE ORGANIZATION PAID WASHINGTON STRATEGIC CONSULTING, INC, A PROFESSIONAL LOBBYING FIRM, FEES TOTALING \$49,530 TO LOBBY FOR LEGISLATION THAT BENEFITS THE ORGANIZATION'S MISSION AND TO KEEP THE ORGANIZATION'S MANAGEMENT INFORMED ABOUT LEGISLATION THAT MAY AFFECT THE ORGANIZATION'S MISSION.

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

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

Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" to Form 990, Part IV, line 6.

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate contributions, aggregate grants, aggregate value, and questions about donor advisement and grant usage.

Part II Conservation Easements. Complete if the organization answered "Yes" to Form 990, Part IV, line 7.

Form for Part II Conservation Easements. Includes checkboxes for purposes of easements, a table for held easements (2a-2d), and questions about monitoring, expenses, and reporting.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.

Complete if the organization answered "Yes" to Form 990, Part IV, line 8.

Form for Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Includes questions about reporting works of art and assets held for public exhibition.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):

- a Public exhibition
- b Scholarly research
- c Preservation for future generations
- d Loan or exchange programs
- e Other _____

4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

Part IV Escrow and Custodial Arrangements. Complete if the organization answered "Yes" to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No

b If "Yes," explain the arrangement in Part XIII and complete the following table:

	Amount
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	1f

2a Did the organization include an amount on Form 990, Part X, line 21? Yes No

b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

Part V Endowment Funds. Complete if the organization answered "Yes" to Form 990, Part IV, line 10.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	436,946.	220,438.			
b Contributions	181,698.	214,976.	220,438.		
c Net investment earnings, gains, and losses	1,871.	1,532.			
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance	620,515.	436,946.	220,438.		

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

- a Board designated or quasi-endowment 4.83 %
- b Permanent endowment 95.17 %
- c Temporarily restricted endowment _____ %

The percentages in lines 2a, 2b, and 2c should equal 100%.

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

	Yes	No
(i) unrelated organizations		X
(ii) related organizations		X

b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?

4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		586,395.	329,620.	256,775.
e Other				

Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).) 256,775.

Part VII Investments - Other Securities.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.) ▶		

Part VIII Investments - Program Related.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.) ▶		

Part IX Other Assets.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶	

Part X Other Liabilities.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

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

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered "Yes" to Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	5,181,409.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains on investments	2a		
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d	130,715.	
e	Add lines 2a through 2d	2e		130,715.
3	Subtract line 2e from line 1		3	5,050,694.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)		5	5,050,694.

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

Complete if the organization answered "Yes" to Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	5,002,050.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a		
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d	166,629.	
e	Add lines 2a through 2d	2e		166,629.
3	Subtract line 2e from line 1		3	4,835,421.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)		5	4,835,421.

Part XIII Supplemental Information.

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

PART X, LINE 2:

EXPLANATION: THE ORGANIZATION ASSESSES ITS TAX POSITION IN ACCORDANCE WITH "ACCOUNTING FOR UNCERTAINTY IN INCOME TAXES" AS PRESCRIBED BY THE ACCOUNTING STANDARDS CODIFICATION, WHICH PROVIDES GUIDANCE FOR FINANCIAL STATEMENT RECOGNITION AND MEASUREMENT OF UNCERTAIN TAX POSITIONS TAKEN OR EXPECTED TO BE TAKEN IN A TAX RETURN FOR OPEN TAX YEARS (GENERALLY A PERIOD OF THREE YEARS FROM THE LATER OF EACH RETURN'S DUE DATE OR THE DATE FILED) THAT REMAIN SUBJECT TO EXAMINATION BY THE ORGANIZATION'S MAJOR TAX JURISDICTIONS.

THE ORGANIZATION BELIEVES THAT IT DOES NOT HAVE ANY SIGNIFICANT UNCERTAIN TAX POSITIONS REQUIRING RECOGNITION OR MEASUREMENT.

Part XIII Supplemental Information (continued)

PART XI, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENT EXPENSE	166,629.
ASSET VALUE ADJUSTMENT	-35,914.
TOTAL TO SCHEDULE D, PART XI, LINE 2D	130,715.

PART XII, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENT EXPENSES	166,629.
------------------------	----------

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events	
		WALK & ROLL	DINNERS / GALAS	206	(add col. (a) through col. (c))	
		(event type)	(event type)	(total number)		
Revenue	1	Gross receipts	1,079,594.	721,445.	1,375,119.	3,176,158.
	2	Less: Contributions	981,127.	644,513.	1,375,119.	3,000,759.
	3	Gross income (line 1 minus line 2)	98,467.	76,932.		175,399.
Direct Expenses	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
	7	Food and beverages				
	8	Entertainment				
	9	Other direct expenses	93,544.	73,085.	0.	166,629.
	10	Direct expense summary. Add lines 4 through 9 in column (d)				166,629.
	11	Net income summary. Subtract line 10 from line 3, column (d)				8,770.

Part III Gaming. Complete if the organization answered "Yes" to Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

		(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue	1	Gross revenue			
Direct Expenses	2	Cash prizes			
	3	Noncash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No
	7	Direct expense summary. Add lines 2 through 5 in column (d)			
	8	Net gaming income summary. Subtract line 7 from line 1, column (d)			

9 Enter the state(s) in which the organization operates gaming activities: _____
 a Is the organization licensed to operate gaming activities in each of these states? Yes No
 b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes No
 b If "Yes," explain: _____

- 11** Does the organization operate gaming activities with nonmembers? Yes No
- 12** Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? Yes No
- 13** Indicate the percentage of gaming activity operated in:
- | | | |
|--------------------------------------|------------|---|
| a The organization's facility | 13a | % |
| b An outside facility | 13b | % |

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶ _____

Address ▶ _____

- 15a** Does the organization have a contract with a third party from whom the organization receives gaming revenue? Yes No
- b** If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ _____ and the amount of gaming revenue retained by the third party ▶ \$ _____.
- c** If "Yes," enter name and address of the third party:

Name ▶ _____

Address ▶ _____

16 Gaming manager information:

Name ▶ _____

Gaming manager compensation ▶ \$ _____

Description of services provided ▶ _____

- Director/officer Employee Independent contractor

17 Mandatory distributions:

- a** Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? Yes No
- b** Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____

Part IV **Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also complete this part to provide any additional information (see instructions).

SCHEDULE G, PART I, LINE 2B, LIST OF TEN HIGHEST PAID FUNDRAISERS:

(I) NAME OF FUNDRAISER: EPIPHANY PRODUCTIONS, INC.

(I) ADDRESS OF FUNDRAISER: 104 HUME AVENUE, ALEXANDRIA, VA 22301

PART I, LINE 2B, COLUMN (V):

EXPLANATION: EPIPHANY PRODUCTIONS, INC WAS PAID TO PROVIDE FUND RAISING AND CONSULTING SERVICES AND ADVICE. THE PAYMENTS DO NOT RELATE TO ANY SPECIFIC SPECIAL EVENT. THE FUNDRAISER DOES NOT TAKE POSSESSION OF ANY

Part IV Supplemental Information (continued)

FUNDS.

FORM 990, SCHEDULE D, PART II, FUNDRAISING EVENTS

EXPLANATION: CURE SMA HAS MULTIPLE CHAPTERS IN MANY STATES WHOSE PURPOSE IS TO RAISE FUNDS FOR THE ORGANIZATION. THE AMOUNTS LISTED IN COLUMNS (A) AND (C) ARE SUMMARY AMOUNTS FOR MULTIPLE SIMILAR EVENTS HELD THROUGH OUT THE COUNTRY. AMOUNTS LISTED IN COLUMN (C) ARE FOR A VARIETY OF EVENTS HELD BY CHAPTERS THROUGHOUT THE COUNTRY.

COLUMN (A): PARTICIPANTS IN THE WALK AND ROLL EVENTS RECEIVE NO DIRECT BENEFITS OTHER THAN A TEE-SHIRT AND ACCESS TO BEVERAGES ALONG THE RACE PATH AND AT THE END OF THE RACE PATH.

COLUMN (C): OTHER EVENTS ARE SIMILAR IN NATURE TO THE CURE SMA WALK AND ROLLS, SUCH AS FUN-RUNS OR 5K RUNS, AND NO OTHER BENEFITS ARE RECEIVED OTHER THAN A TEE-SHIRT OR RACE BEVERAGES. OTHER EVENTS ARE NOT HELD UNDER THE NATIONALLY BRANDED NAME "WALK AND ROLL" WHICH ARE COORDINATED AND PROMOTED AS A NATION-WIDE FUNDRAISING EVENT BY CURE SMA.

**SCHEDULE I
(Form 990)**

Department of the Treasury
Internal Revenue Service

**Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States**
Complete if the organization answered "Yes" to Form 990, Part IV, line 21 or 22.
▶ **Attach to Form 990.**

OMB No. 1545-0047

2013

**Open to Public
Inspection**

▶ **Information about Schedule I (Form 990) and its instructions is at www.irs.gov/form990**

Name of the organization **FAMILIES OF SPINAL MUSCULAR ATROPHY** Employer identification number **36-3320440**

Part I General Information on Grants and Assistance

- 1** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? **Yes** **No**
- 2** Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
INDIANA UNIVERSITY 620 UNION DRIVE, RM 518 INDIANAPOLIS, IN 46202	35-6001373	501(C)(3)	30,312.	0.			IDENTIFY AND RECRUIT SMA PATIENTS AND FAMILIES. TRACK RESEARCH STUDIES, EXPAND AWARENESS AND THE
THE UNIVERSITY OF SOUTHERN CALIFORNIA - 837 DOWNEY WAY - LOS ANGELES, CA 96150	95-6006143	501(C)(3)	75,000.	0.			RESEARCH OF NOVEL NEUROMUSCULAR PREPARATIONS
THE RESEARCH INSTITUTE AT NATIONWIDE CHILDREN'S HOSPITAL - 700 CHILDREN'S DRIVE - COLUMBUS, OH 43205	31-1036372	501(C)(3)	125,000.	0.			IND ENABLINGS STUDIES FOR A CNS DELIVERED GENE THERAPY
UNIVERSITY OF COLORADO-DENVER PO BOX 910238 DENVER, CO 80291	84-6000555	501(C)(3)	95,000.	0.			RESEARCH GRANT
CALIFORNIA INSTITUTE OF BIOMEDICAL RESEARCH - 10931 NORTH TORREY PINES ROAD - LA JOLLA, CA 92037	45-3682796	501(C)(3)	195,000.	0.			RESEARCH GRANT - DRUG DISCOVERY
COLD SPRING HARBOR LABRATORY ONE BUNGTOWN ROAD COLD SPRING HARBOR, NY 11724	11-2013303	501(C)(3)	150,000.	0.			RESEARCH GRANT - DRUG DISCOVERY

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **10.**
- 3** Enter total number of other organizations listed in the line 1 table

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

Schedule I (Form 990) (2013)

SEE PART IV FOR COLUMN (H) DESCRIPTIONS

Part II Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part II.)

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
UNIVERSITY OF EDINBURGH OLD COLLEGE SOUTH BRIDGE EDINBURGH, UNITED KINGDOM	94-3145385	501(C)(3)	55,000.	0.			RESEARCH GRANT
THE JACKSON LABRATORY 600 MAIN ST BAR HARBOR, ME 04609	01-0211513	501(C)(3)	89,342.	0.			RESEARCH GRANT
HENRY M JACKSON FOUNDATION FOR THE ADVANCEMENT OF MILITARY MEDICINE - 6720 A ROCKLEDGE DR - BETHESDA , MD 20817	52-1317896	501(C)(3)	95,000.	0.			RESEARCH GRANT
THE MEDICAL COLLEGE OF WISCONSIN 8701 WATERTOWN PLANK ROAD MILWAUKEE, WI 53226	39-0806261	501(C)(3)	95,000.	0.			RESEARCH GRANT

Part III **Grants and Other Assistance to Individuals in the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance

Part IV **Supplemental Information.** Provide the information required in Part I, line 2, Part III, column (b), and any other additional information.

PART I, LINE 2:

EXPLANATION: DETAILED REQUIREMENTS MADE OF RECIPIENTS IN GRANT CONTRACTS:

RECIPIENTS SHALL PROVIDE THE ORGANIZATION WITH REPORTS OF THE WORK

PERFORMED UNDER THIS AGREEMENT IN ACCORDANCE WITH THE FOLLOWING SCHEDULE:

**QUARTERLY WRITTEN PROGRESS REPORTS DUE WITHIN THIRTY (30) DAYS AFTER THE
END OF THE QUARTER.**

Part IV Supplemental Information

RECIPIENTS SHALL ALSO SUBMIT TO THE ORGANIZATION A COMPREHENSIVE FINAL REPORT WITHIN NINETY (90) DAYS OF TERMINATION OF THE RESEARCH PROJECT.

FOR THE PURPOSE OF IDENTIFYING PATENTABLE INVENTIONS NOT COVERED BY PRE EXISTING PATENTS, RECIPIENTS SHALL SUBMIT A COPY OF ALL PROPOSED PUBLICATIONS, PAPERS, AND ANY OTHER WRITTEN DISCLOSURE OF SUCH DATA OR INFORMATION TO THE ORGANIZATION AT LEAST THIRTY (30) DAYS PRIOR TO SUBMISSION FOR PUBLICATION OR DISCLOSURE TO A THIRD PARTY.

PART II, LINE 1, COLUMN (H):

NAME OF ORGANIZATION OR GOVERNMENT: INDIANA UNIVERSITY

(H) PURPOSE OF GRANT OR ASSISTANCE: IDENTIFY AND RECRUIT SMA PATIENTS AND FAMILIES. TRACK RESEARCH STUDIES, EXPAND AWARENESS AND THE USE OF THE REGISTRY.

SCHEDULE I, PART II

CERTAIN GRANT PAYMENTS ARE MADE TO GRANTEES BASED ON RESEARCH MILESTONES BEING MET. THESE AMOUNTS ARE NOT INCLUDED IN THE GRANTS PAYABLE. AS OF THE END OF THE CURRENT YEAR, FUTURE AMOUNTS OF THESE PAYMENTS ARE ESTIMATED TO BE \$410,000.

**SCHEDULE J
(Form 990)**

Department of the Treasury
Internal Revenue Service

Compensation Information

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.
▶ Attach to Form 990. ▶ See separate instructions.

▶ Information about Schedule J (Form 990) and its instructions is at www.irs.gov/form990

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

Part I Questions Regarding Compensation

	Yes	No								
<p>1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed in Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.</p> <table border="0"> <tr> <td><input type="checkbox"/> First-class or charter travel</td> <td><input type="checkbox"/> Housing allowance or residence for personal use</td> </tr> <tr> <td><input type="checkbox"/> Travel for companions</td> <td><input type="checkbox"/> Payments for business use of personal residence</td> </tr> <tr> <td><input type="checkbox"/> Tax indemnification and gross-up payments</td> <td><input type="checkbox"/> Health or social club dues or initiation fees</td> </tr> <tr> <td><input type="checkbox"/> Discretionary spending account</td> <td><input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef)</td> </tr> </table>	<input type="checkbox"/> First-class or charter travel	<input type="checkbox"/> Housing allowance or residence for personal use	<input type="checkbox"/> Travel for companions	<input type="checkbox"/> Payments for business use of personal residence	<input type="checkbox"/> Tax indemnification and gross-up payments	<input type="checkbox"/> Health or social club dues or initiation fees	<input type="checkbox"/> Discretionary spending account	<input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef)		
<input type="checkbox"/> First-class or charter travel	<input type="checkbox"/> Housing allowance or residence for personal use									
<input type="checkbox"/> Travel for companions	<input type="checkbox"/> Payments for business use of personal residence									
<input type="checkbox"/> Tax indemnification and gross-up payments	<input type="checkbox"/> Health or social club dues or initiation fees									
<input type="checkbox"/> Discretionary spending account	<input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef)									
b If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain	1b									
2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked in line 1a?	2									
<p>3 Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.</p> <table border="0"> <tr> <td><input type="checkbox"/> Compensation committee</td> <td><input type="checkbox"/> Written employment contract</td> </tr> <tr> <td><input type="checkbox"/> Independent compensation consultant</td> <td><input type="checkbox"/> Compensation survey or study</td> </tr> <tr> <td><input type="checkbox"/> Form 990 of other organizations</td> <td><input checked="" type="checkbox"/> Approval by the board or compensation committee</td> </tr> </table>	<input type="checkbox"/> Compensation committee	<input type="checkbox"/> Written employment contract	<input type="checkbox"/> Independent compensation consultant	<input type="checkbox"/> Compensation survey or study	<input type="checkbox"/> Form 990 of other organizations	<input checked="" type="checkbox"/> Approval by the board or compensation committee				
<input type="checkbox"/> Compensation committee	<input type="checkbox"/> Written employment contract									
<input type="checkbox"/> Independent compensation consultant	<input type="checkbox"/> Compensation survey or study									
<input type="checkbox"/> Form 990 of other organizations	<input checked="" type="checkbox"/> Approval by the board or compensation committee									
4 During the year, did any person listed in Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:										
a Receive a severance payment or change-of-control payment?	4a	X								
b Participate in, or receive payment from, a supplemental nonqualified retirement plan?	4b	X								
c Participate in, or receive payment from, an equity-based compensation arrangement?	4c	X								
If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.										
Only section 501(c)(3) and 501(c)(4) organizations must complete lines 5-9.										
5 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:										
a The organization?	5a	X								
b Any related organization?	5b	X								
If "Yes" to line 5a or 5b, describe in Part III.										
6 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:										
a The organization?	6a	X								
b Any related organization?	6b	X								
If "Yes" to line 6a or 6b, describe in Part III.										
7 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization provide any non-fixed payments not described in lines 5 and 6? If "Yes," describe in Part III	7	X								
8 Were any amounts reported in Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III	8	X								
9 If "Yes" to line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?	9									

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

Schedule J (Form 990) 2013

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported in Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that are not listed on Form 990, Part VII.

Note. The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation reported as deferred in prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
(1) KENNETH HOBBY PRESIDENT	(i)	145,167.	0.	0.	0.	8,229.	153,396.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
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	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							

**SCHEDULE M
(Form 990)**

Noncash Contributions

OMB No. 1545-0047

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

- ▶ Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
- ▶ Attach to Form 990.
- ▶ Information about Schedule M (Form 990) and its instructions is at www.irs.gov/form990

Name of the organization **FAMILIES OF SPINAL MUSCULAR ATROPHY** Employer identification number **36-3320440**

Part I	Types of Property	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1	Art - Works of art				
2	Art - Historical treasures				
3	Art - Fractional interests				
4	Books and publications				
5	Clothing and household goods				
6	Cars and other vehicles				
7	Boats and planes				
8	Intellectual property				
9	Securities - Publicly traded	X	6	19,424.	FAIR MARKET VALUE
10	Securities - Closely held stock				
11	Securities - Partnership, LLC, or trust interests				
12	Securities - Miscellaneous				
13	Qualified conservation contribution - Historic structures				
14	Qualified conservation contribution - Other				
15	Real estate - Residential				
16	Real estate - Commercial				
17	Real estate - Other				
18	Collectibles				
19	Food inventory				
20	Drugs and medical supplies				
21	Taxidermy				
22	Historical artifacts				
23	Scientific specimens				
24	Archeological artifacts				
25	Other ▶ (<u>SEE PART II</u>)	X	1	85,675.	RETAIL RENTAL VALUE
26	Other ▶ (_____)				
27	Other ▶ (_____)				
28	Other ▶ (_____)				

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement **29**

	Yes	No
30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 - 28, that it must hold for at least three years from the date of the initial contribution, and which is not required to be used for exempt purposes for the entire holding period?		X
b If "Yes," describe the arrangement in Part II.		
31 Does the organization have a gift acceptance policy that requires the review of any non-standard contributions?		X
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?		X
b If "Yes," describe in Part II.		
33 If the organization did not report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.		

Part II **Supplemental Information.** Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

SCHEDULE M, LINE 33:

EXPLANATION:

PAGE 1, LINE 25: DONATED RENTAL EQUIPMENT FOR SPECIAL EVENTS

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.

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

OMB No. 1545-0047

2013

Open to Public
Inspection

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

DEVELOPING A TREATMENT AND CURE FOR SPINAL MUSCULAR ATROPHY; PROVIDING
RESOURCES FOR PATIENTS & FAMILIES.

FORM 990, PART III, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

CLINICAL TRIALS, PROVIDE REAL HOPE FOR FAMILIES AND PATIENTS IMPACTED
BY THE DISEASE. THE CHARITY HAS INVESTED OVER \$57 MILLION IN RESEARCH
AND BEEN INVOLVED IN FUNDING HALF OF ALL THE ONGOING NOVEL DRUG
PROGRAMS FOR SMA. CURE SMA IS A NONPROFIT 501(C)(3) ORGANIZATION, WITH
31 CHAPTERS AND 110,000 MEMBERS AND SUPPORTERS THROUGHOUT THE UNITED
STATES, AND IS DEDICATED TO CREATING A TREATMENT AND CURE BY: FUNDING
AND ADVANCING A COMPREHENSIVE RESEARCH PROGRAM; SUPPORTING SMA FAMILIES
THROUGH NETWORKING, INFORMATION AND SERVICES; IMPROVING CARE FOR ALL
SMA PATIENTS; EDUCATING HEALTHCARE PROFESSIONALS AND THE PUBLIC ABOUT
SMA; ENLISTING GOVERNMENT SUPPORT FOR SMA; EMBRACING ALL TOUCHED BY SMA
IN A CARING COMMUNITY.

FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:

PROGRAMS SUCH AS THE EQUIPMENT POOL, FREE OF CHARGE TO MEMBERS OF CURE
SMA. THE POOL INCLUDES A WIDESPREAD LIST OF EQUIPMENT SUITABLE FOR SMA
CHILDREN. WE ALSO OFFER THE "ASK THE EXPERT" SERVICE WHERE FAMILIES
CAN GET ANSWERS TO IMPORTANT HEALTH-RELATED QUESTIONS FROM SMA
PHYSICIANS AND CLINICIANS.

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS:

HAS FUNDED ALMOST TWO THIRDS OF ALL THE ONGOING DRUG PROGRAMS FOR SMA.

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

Schedule O (Form 990 or 990-EZ) (2013)

332211
09-04-13

Name of the organization FAMILIES OF SPINAL MUSCULAR ATROPHY	Employer identification number 36-3320440
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CLEAR EVIDENCE OF PROGRESS IS BEING SEEN:

- 1) PROGRAMS ARE ADVANCING INTO THE CLINICAL TRIAL STAGE OF TESTING.
- 2) THERE IS BROAD DIVERSITY OF APPROACHES IN DEVELOPMENT.
- 3) THE TOTAL NUMBER OF PROGRAMS IS GROWING.
- 4) FUNDING AND RESOURCES FROM GOVERNMENT AND INDUSTRY ARE INCREASING.

CLINICAL PROGRAMS

OUR COMMUNITY HAS SEEN SUCCESS OVER RECENT YEARS IN ADVANCING BASIC RESEARCH DISCOVERIES FROM THE BENCH TO THE CLINIC. THERE ARE NOW 5 NOVEL PROGRAMS TESTING DRUGS IN HUMAN CLINICAL TRIALS FOR SMA: CURE SMA IS ATTACKING THE DISEASE FROM EVERY ANGLE POSSIBLE, AND THERE ARE NOW MORE NEW DRUG PROGRAMS IN DEVELOPMENT THAN AT ANY OTHER TIME.

FORM 990, PART VI, SECTION B, LINE 11:

EXPLANATION:

THE EXECUTIVE COMMITTEE OF THE BOARD AND THE PRESIDENT PERFORM AN INITIAL REVIEW OF FORM 990. AFTER ACCEPTANCE OF FORM 990 BY THE EXECUTIVE COMMITTEE OF THE BOARD AND THE PRESIDENT, FORM 990 IS EMAILED TO THE FULL BOARD FOR REVIEW AND COMMENT BEFORE IT IS FILED.

FORM 990, PART VI, SECTION B, LINE 12C:

EXPLANATION:

MEMBERS OF THE BOARD OF DIRECTORS ARE REQUIRED TO SIGN AN ANNUAL STATEMENT DISCLOSING ANY POSSIBLE CONFLICTS OF INTEREST.

FORM 990, PART VI, SECTION B, LINE 15:

EXPLANATION:

332212
09-04-13

Name of the organization FAMILIES OF SPINAL MUSCULAR ATROPHY	Employer identification number 36-3320440
--	---

PRESIDENT'S COMPENSATION - APPROVED BY THE BOARD OF DIRECTORS. THE BOARD'S EXECUTIVE COMMITTEE CONDUCTS A MARKET SURVEY OF THE POSITION USING INDEPENDENT COMPENSATION SOURCES, AND THEN PRESENTS A RECOMMENDATION TO THE FULL BOARD FOR APPROVAL.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:
AL, AZ, CA, CO, CT, FL, IA, IL, KS, LA, MA, MI, AK, MN, NJ, NY, OH, PA, TN, TX, WA, WI, NM, NC, SC
UT, AR, KY, OR, ME, WV, GA

FORM 990, PART VI, SECTION C, LINE 19:
EXPLANATION:
THE ORGANIZATION'S GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY AND FINANCIAL STATEMENTS ARE AVAILABLE UPON REQUEST. THE REQUEST FOR DOCUMENTS CAN BE MADE IN WRITING OR BY PHONE BY CONTACTING THE NATIONAL OFFICE. WHEN A REQUEST IS MADE FOR DOCUMENTS, THE EXECUTIVE COMMITTEE OF THE BOARD OF DIRECTORS APPROVES THE RELEASE OF THE DOCUMENTS.

FORM 990, PART XI, LINE 9, CHANGES IN NET ASSETS:
ASSET VALUE ADJUSTMENT -35,914.

FORM 990, PAGE 12, PART XII, QUESTION 2C:
EXPLANATION: NO CHANGES WERE MADE TO THE AUDIT OVERSIGHT PROCESS FOR THE CURRENT YEAR.