

Form **990**
Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)
Do not enter social security numbers on this form as it may be made public
Information about Form 990 and its instructions is at www.irs.gov/form990

OMB No 1545-0047
2016
Open to Public Inspection

A For the 2016 calendar year, or tax year beginning 07-01-2016, and ending 06-30-2017

- B** Check if applicable
 Address change
 Name change
 Initial return
 Final
 Return/terminated
 Amended return
 Application pending

C Name of organization
FAMILIES OF SPINAL MUSCULAR ATROPHY

Doing business as
CURE SMA

Number and street (or P O box if mail is not delivered to street address) Room/suite
925 BUSSE ROAD

City or town, state or province, country, and ZIP or foreign postal code
ELK GROVE VILLAGE, IL 60007

D Employer identification number
36-3320440

E Telephone number
(800) 886-1762

G Gross receipts \$ 8,630,278

F Name and address of principal officer
KENNETH HOBBY
925 BUSSE ROAD
ELK GROVE VILLAGE, IL 60007

H(a) Is this a group return for subordinates? Yes No
H(b) Are all subordinates included? Yes No
If "No," attach a list (see instructions)
H(c) Group exemption number ▶

I Tax-exempt status 501(c)(3) 501(c) () ◀(insert no) 4947(a)(1) or 527

J Website: ▶ WWW CURESMA ORG

K Form of organization Corporation Trust Association Other ▶

L Year of formation 1984

M State of legal domicile IL

Part I Summary

1 Briefly describe the organization's mission or most significant activities
CURE SMA LEADS THE WAY TO A WORLD WITHOUT SPINAL MUSCULAR ATROPHY, THE NUMBER ONE GENETIC CAUSE OF DEATH FOR INFANTS CURE SMA FUNDS AND DIRECTS COMPREHENSIVE RESEARCH THAT DRIVES BREAKTHROUGHS IN TREATMENT AND CARE, AND PROVIDES FAMILIES THE SUPPORT THEY NEED FOR TODAY

2 Check this box 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)	3	14
4 Number of independent voting members of the governing body (Part VI, line 1b)	4	14
5 Total number of individuals employed in calendar year 2016 (Part V, line 2a)	5	32
6 Total number of volunteers (estimate if necessary)	6	6,600
7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0
7b Net unrelated business taxable income from Form 990-T, line 34	7b	0

	Prior Year	Current Year
8 Contributions and grants (Part VIII, line 1h)	5,149,322	5,818,435
9 Program service revenue (Part VIII, line 2g)	815,371	1,381,841
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	-6,037	23,825
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	151,130	649,175
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	6,109,786	7,873,276
13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	1,219,840	977,500
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)	1,747,547	2,465,061
16a Professional fundraising fees (Part IX, column (A), line 11e)	24,159	2,500
b Total fundraising expenses (Part IX, column (D), line 25) ▶1,009,256		
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	2,875,998	4,120,956
18 Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	5,867,544	7,566,017
19 Revenue less expenses Subtract line 18 from line 12	242,242	307,259

	Beginning of Current Year	End of Year
20 Total assets (Part X, line 16)	3,916,800	4,984,542
21 Total liabilities (Part X, line 26)	1,601,166	2,289,429
22 Net assets or fund balances Subtract line 21 from line 20	2,315,634	2,695,113

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: 2017-11-08
Type or print name and title: KENNETH HOBBY PRESIDENT

Paid Preparer Use Only
Print/Type preparer's name: JANET FIFER
Preparer's signature: JANET FIFER
Date: 2017-11-02
Check if self-employed
PTIN: P01225772
Firm's name: KAUFMAN ROSSIN & CO PA
Firm's EIN: 59-1818353
Firm's address: 2699 S BAYSHORE DRIVE
Phone no: (305) 858-5600
MIAMI, FL 33133

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission

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 CLINICAL TRIALS, PROVIDE REAL HOPE FOR FAMILIES AND PATIENTS IMPACTED BY THE DISEASE THE CHARITY HAS INVESTED OVER \$60 MILLION IN RESEARCH AND HAS BEEN INVOLVED IN FUNDING HALF OF ALL THE ONGOING NOVEL DRUG PROGRAMS FOR SMA CURE SMA IS A NONPROFIT 501 (C)3 ORGANIZATION, WITH 34 CHAPTERS AND 115,000 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 (

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 No

If "Yes," describe these new services on Schedule O

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

If "Yes," describe these changes on Schedule O

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 \$ 949,094 including grants of \$) (Revenue \$)
See Additional Data

4b (Code) (Expenses \$ 3,099,625 including grants of \$ 977,500) (Revenue \$ 320,298)
See Additional Data

4c (Code) (Expenses \$ 2,171,808 including grants of \$) (Revenue \$ 1,061,543)
See Additional Data

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

4e Total program service expenses ▶ 6,220,527

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

Part IV Checklist of Required Schedules (continued)

	Yes	No
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	Yes	
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>		No
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>	Yes	
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>		No
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
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?		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>		No
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>		No
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? <i>If "Yes," complete Schedule L, Part II</i>		No
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>		No
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>		No
b A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		No
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>		No
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	Yes	
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>		No
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		No
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>		No
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>		No
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>		No
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		No
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>		
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>		No
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>		No
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O	Yes	

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

Table with columns for question ID, question text, and Yes/No response boxes. Includes sections for backup withholding, employee reporting, foreign accounts, prohibited transactions, charitable contributions, and 501(c)(7), (12), and (29) organizations.

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 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 Enter the number of voting members of the governing body at the end of the tax year (14); 1b Enter the number of voting members included in line 1a, above, who are independent (14); 2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee? (No); 3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person? (No); 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? (No); 5 Did the organization become aware during the year of a significant diversion of the organization's assets? (No); 6 Did the organization have members or stockholders? (No); 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? (No); 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? (No); 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a The governing body? (Yes); 8b Each committee with authority to act on behalf of the governing body? (Yes); 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O (No)

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 Did the organization have local chapters, branches, or affiliates? (Yes); 10b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? (Yes); 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? (Yes); 11b Describe in Schedule O the process, if any, used by the organization to review this Form 990; 12a Did the organization have a written conflict of interest policy? If "No," go to line 13 (Yes); 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? (Yes); 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done (Yes); 13 Did the organization have a written whistleblower policy? (Yes); 14 Did the organization have a written document retention and destruction policy? (Yes); 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? 15a The organization's CEO, Executive Director, or top management official (Yes); 15b Other officers or key employees of the organization (Yes); If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions); 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? (No); 16b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?

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, NJ, NY, OH, TN, TX, WA, AK, VA, NC, SC, UT, AR, KY, ME, WV, GA, DE, HI, ID, IN, MD, MT, ND, NE, NV, NH, OK, SD, VT, WI, WY, NM, MN, MS, MA, MI, MO, OR, RI, PA, DC
- 18 Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply: [X] Own website [] Another's website [X] Upon request [] Other (explain in Schedule O)
- 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, address, and telephone number of the person who possesses the organization's books and records: KENNETH HOBBY 925 BUSSE ROAD ELK GROVE VILLAGE, IL 60007 (800) 886-1762

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, or 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 dotted 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	15 00	X		X				0	0	0
(2) KELLY COLE SECRETARY	6 00	X		X				0	0	0
(3) BRAD NUNEMAKER TREASURER	6 00	X		X				0	0	0
(4) DOUGLAS KERR DIRECTOR	2 00	X						0	0	0
(5) COREY BRAASTAD DIRECTOR	2 00	X						0	0	0
(6) DOUGLAS ERWIN DIRECTOR	2 00	X						0	0	0
(7) THOMAS MURRAY DIRECTOR	2 00	X						0	0	0
(8) MELISSA MILINOVICH DIRECTOR	2 00	X						0	0	0
(9) STEVE RAGLAND DIRECTOR	2 00	X						0	0	0
(10) SHANNON SHRYNE DIRECTOR	2 00	X						0	0	0
(11) GREG ZERZAN DIRECTOR	2 00	X						0	0	0
(12) ANNIE KENNEDY DIRECTOR	2 00	X						0	0	0
(13) SPENCER PERLMAN DIRECTOR	2 00	X						0	0	0
(14) JOHN PORTER DIRECTOR	2 00	X						0	0	0
(15) ROBERT LOCKWOOD DIRECTOR	2 00	X						0	0	0
(16) KENNETH HOBBY PRESIDENT	70 00			X				182,099	0	14,664
(17) JILL JARECKI RESEARCH DIRECTOR	50 00					X		171,689	0	628

Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted 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			
(18) SUSAN KOVACH FINANCE & ADMIN DIRECTOR	60 00					X		114,996	0	628

1b Sub-Total			
c Total from continuation sheets to Part VII, Section A			
d Total (add lines 1b and 1c)	468,784	0	15,920

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization **3**

	Yes	No
3 Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		No
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>	Yes	
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		No

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization Report compensation for the calendar year ending with or within the organization's tax year

(A) Name and business address	(B) Description of services	(C) Compensation
MCDERMOTT WILL & EMERY LLP 272 MIDDLEFIELD ROAD SUITE 100 MENLO PART, CA 94025	LEGAL SERVCIES	257,062
DRINKER BIDDLE & REATH LLP 1500 K STREET NW WASHINGTON, DC 20005	LEGAL AND LOBBYING SERVICES	131,881

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization **2**

Part VIII Statement of Revenue

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants and Other Similar Amounts	1a Federated campaigns	1a					
	b Membership dues	1b					
	c Fundraising events	1c	3,134,377				
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above	1f	2,684,058				
	g Noncash contributions included in lines 1a-1f \$ _____		371,235				
	h Total. Add lines 1a-1f		5,818,435				
Program Service Revenue		Business Code					
	2a ANNUAL CONFERENCE		900099	1,061,543	1,061,543		
	b INDUSTRY COLLABORATION		900099	320,298	320,298		
	c _____						
	d _____						
	e _____						
	f All other program service revenue						
g Total. Add lines 2a-2f		1,381,841					
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			20,834		20,834	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6a Gross rents	(i) Real	(ii) Personal				
		b Less rental expenses					
		c Rental income or (loss)					
		d Net rental income or (loss)					
	7a Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other				
		b Less cost or other basis and sales expenses					
		c Gain or (loss)					
		d Net gain or (loss)			2,991		2,991
	8a Gross income from fundraising events (not including \$ 3,134,377 of contributions reported on line 1c) See Part IV, line 18	a					
		b Less direct expenses			502,807		
		c Net income or (loss) from fundraising events			496,065		6,742
	9a Gross income from gaming activities See Part IV, line 19	a					
b Less direct expenses							
c Net income or (loss) from gaming activities							
10a Gross sales of inventory, less returns and allowances	a						
	b Less cost of goods sold			15,773			
	c Net income or (loss) from sales of inventory			23,873	-8,100	-8,100	
11a SEE SCHEDULE O	Miscellaneous Revenue	Business Code					
	b OUTLICENSING		900099	585,000	585,000		
	c _____						
	d All other revenue						
	e Total. Add lines 11a-11d			65,533	65,533		
12 Total revenue. See Instructions			7,873,276	2,024,274	0	30,567	

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

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.				
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21.	592,500	592,500		
2 Grants and other assistance to domestic individuals. See Part IV, line 22.				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, line 15 and 16.	385,000	385,000		
4 Benefits paid to or for members.				
5 Compensation of current officers, directors, trustees, and key employees.	218,855	151,010	37,205	30,640
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.	1,917,325	1,364,890	104,497	447,938
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions).	28,129	21,192	1,325	5,612
9 Other employee benefits.	129,286	91,064	6,468	31,754
10 Payroll taxes.	171,466	120,036	12,459	38,971
11 Fees for services (non-employees)				
a Management.				
b Legal.	101,399	80,751		20,648
c Accounting.	38,588		38,588	
d Lobbying.	123,086	123,086		
e Professional fundraising services. See Part IV, line 17.	2,500			2,500
f Investment management fees.	6,701		6,701	
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	18,209	2,625	8,573	7,011
12 Advertising and promotion.	136,227	95,919	9,414	30,894
13 Office expenses.	431,754	328,586	18,977	84,191
14 Information technology.	114,713	86,035	5,736	22,942
15 Royalties.				
16 Occupancy.	149,047	104,482	10,377	34,188
17 Travel.				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials.				
19 Conferences, conventions, and meetings.	1,377,797	1,221,871	70,009	85,917
20 Interest.				
21 Payments to affiliates.				
22 Depreciation, depletion, and amortization.	148,136	131,097	3,408	13,631
23 Insurance.	17,982	12,587	1,259	4,136
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	737,310	605,880	46	131,384
b SMA RESEARCH EXPENSES	570,709	570,709		
c PATIENT SERVICES	120,000	120,000		
d MISCELLANEOUS	29,298	11,207	1,192	16,899
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e.	7,566,017	6,220,527	336,234	1,009,256
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 <input type="checkbox"/> 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 IX

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	1,961,915	1	2,251,340
	2 Savings and temporary cash investments	696,160	2	875,061
	3 Pledges and grants receivable, net	76,550	3	209,652
	4 Accounts receivable, net	89,780	4	327,032
	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 instructions) Complete Part II of Schedule L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	16,413	9	49,845
	10a Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	381,064		
	b Less accumulated depreciation	165,107		
	11 Investments—publicly traded securities	854,008	11	1,032,313
	12 Investments—other securities See Part IV, line 11	547	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	22,795
16 Total assets. Add lines 1 through 15 (must equal line 34)	3,916,800	16	4,984,542	
Liabilities	17 Accounts payable and accrued expenses	622,416	17	1,299,429
	18 Grants payable	978,750	18	990,000
	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	1,601,166	26	2,289,429
Net Assets or Fund Balances	27 Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34. Unrestricted net assets	1,186,315	27	1,212,123
	28 Temporarily restricted net assets	305,881	28	484,392
	29 Permanently restricted net assets	823,438	29	998,598
	30 Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34. 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	2,315,634	33	2,695,113
	34 Total liabilities and net assets/fund balances	3,916,800	34	4,984,542

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	7,873,276
2	Total expenses (must equal Part IX, column (A), line 25)	2	7,566,017
3	Revenue less expenses Subtract line 2 from line 1	3	307,259
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	2,315,634
5	Net unrealized gains (losses) on investments	5	72,220
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	0
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	2,695,113

Part XII Financial Statements and Reporting

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

		Yes	No
<p>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</p>			
<p>2a Were the organization's financial statements compiled or reviewed by an independent accountant? 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</p>	2a		No
<p>b Were the organization's financial statements audited by an independent accountant? 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</p>	2b	Yes	
<p>c 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? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O</p>	2c	Yes	
<p>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?</p>	3a		No
<p>b 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</p>	3b		

Additional Data

Software ID:

Software Version:

EIN: 36-3320440

Name: FAMILIES OF SPINAL MUSCULAR ATROPHY

Form 990 (2016)

Form 990, Part III, Line 4a:

INDIVIDUALS WITH SMA NEED SPECIALIZED CARE AND EQUIPMENT, WHICH CAN PUT ENORMOUS EMOTIONAL, LOGISTICAL, AND FINANCIAL PRESSURE ON FAMILIES. CURE SMA IS COMMITTED TO MAKING SURE THAT FAMILIES HAVE THE BEST, MOST ACCURATE INFORMATION ABOUT SMA AND WHAT IT MEANS FOR THEM, AND TO MAKING SURE THAT THEY UNDERSTAND ALL THE OPTIONS AND RESOURCES AVAILABLE TO THEM FROM DAY-TO-DAY CARE TO THE CHANGING LANDSCAPE OF RESEARCH BREAKTHROUGHS. THIS INCLUDES OUR CARE SERIES BOOKLETS, WHICH ARE SENT OUT AS PART OF INFORMATIONAL PACKETS AVAILABLE AT NO COST TO ANYONE WHO REQUESTS ONE. DEVELOPED BY MEDICAL EXPERTS AND REVIEWED BY FAMILIES, THESE BOOKLETS COVER TOPICS SUCH AS BREATHING, NUTRITION, PALLIATIVE CARE, GENETICS, MUSCULOSKELETAL ISSUES, AND MORE. IN ADDITION, OUR EQUIPMENT POOL GIVES FAMILIES ACCESS TO SPECIALIZED ITEMS LIKE CAR BEDS, STROLLERS AND BATHING SYSTEMS AT NO COST. EVERY NEWLY-DIAGNOSED FAMILY RECEIVES A CARE PACKAGE FROM CURE SMA, FULL OF TOYS APPROPRIATE TO THE CHILD'S TYPE OF THE DISEASE, IMPARTIAL INFORMATION FOR PARENTS, AND USEFUL ITEMS SUGGESTED BY OTHER SMA PARENTS BASED ON THEIR OWN EXPERIENCES. CURE SMA ALSO EDUCATE THE PUBLIC ABOUT SMA, TO STRENGTHEN THE SUPPORT AVAILABLE TO FAMILIES. THIS INCLUDES DIRECTIONS, A BIENNIAL FAMILY SUPPORT NEWSLETTER, AND COMPASS, A QUARTERLY UPDATE ON RESEARCH DEVELOPMENTS. CURE SMA WORKS DIRECTLY WITH CLINICIANS, MEDICAL DOCTORS, SPECIALISTS, AND SKILLED CAREGIVERS TO ENSURE THAT PATIENTS HAVE ACCESS TO THE BEST POSSIBLE CARE.

Form 990, Part III, Line 4b:

CURE SMA FOCUSES ON THREE DIFFERENT YET EQUALLY CRITICAL AND INTERDEPENDENT RESEARCH AREAS BASIC RESEARCH, TO UNDERSTAND THE CAUSE AND BIOLOGY OF SMA, DRUG DISCOVERY, TO CONVERT BASIC RESEARCH IDEAS INTO PRACTICAL NEW DRUG CANDIDATES, AND CLINICAL & REGULATORY RESEARCH, TO PROVIDE THE INFRASTRUCTURE TO TEST THE DRUG CANDIDATES DURING THIS PERIOD CURE SMA FUNDED 15 NEW AND ONGOING BASIC RESEARCH GRANTS, AS WELL AS 4 ONGOING DRUG DISCOVERY PROJECTS WE ALSO FUNDED AND EXECUTED MULTIPLE CLINICAL AND REGULATORY FOCUSED PROJECTS, INCLUDING NOMINATING SMA FOR INCLUSION ON THE FEDERAL UNIFORM RECOMMENDED SCREENING PANEL AND HOLDING A EXTERNALLY-LED PATIENT FOCUSED DRUG DEVELOPMENT MEETING WITH THE FDA CURE SMA ALSO PROVIDES PATIENT AND CLINICAL CARE EDUCATION, WITH EXPERTISE FROM ITS MEDICAL ADVISORY COUNCIL IT ALSO IS IN THE BEGINNING STAGES OF LAUNCHING A MULTI-CENTER CLINICAL DATA REGISTRY WITHIN AN ACCREDITED CARE CENTER NETWORK WITH THE FIRST FDA-APPROVED THERAPY COMING IN DECEMBER 2016, THE TEAM DEVOTED RESOURCES TO COMPILING A LIST OF ACCESS CENTERS FOR PATIENTS CURRENTLY, THERE IS ONE APPROVED DRUG FOR SMA, WITH ANOTHER 19 DRUG PROGRAMS IN DEVELOPMENT, INCLUDING FIVE IN CLINICAL TRIALS CURE SMA HAS FUNDED HALF OF ALL THE ONGOING DRUG PROGRAMS IN SMA, INCLUDING FUNDING SIX DRUG PROGRAMS THIS YEAR

Form 990, Part III, Line 4c:

WE HOSTED OUR 28TH ANNUAL SMA CONFERENCE IN ORLANDO, FL, WITH OVER 2,073 TOTAL ATTENDEES. OUR ANNUAL CONFERENCE IS AN INVALUABLE RESOURCE FOR THE ENTIRE SMA COMMUNITY, BRINGING TOGETHER RESEARCHERS, CLINICIANS, AND FAMILIES TO NETWORK, LEARN, AND COLLABORATE. THE CONFERENCE IS THE LARGEST IN THE WORLD FOCUSED SPECIFICALLY ON SMA, AND IT ATTRACTS THE TOP SCIENTISTS AND COMPANIES IN THE FIELD. THE FAMILY CONFERENCE INCLUDES A VARIETY OF WORKSHOPS, KEYNOTE SESSIONS WITH LEADING RESEARCHERS, A FAMILY-FRIENDLY RESEARCH POSTER SESSION, AND MORE-PLUS FUN EVENTS LIKE OUR DANCE PARTY, MEET-AND-GREET, PAJAMA PARTY AND MOVIE NIGHT, AND TEEN AND ADULT SOCIAL ACTIVITIES. THE RESEARCHER CONFERENCE CREATES OPEN COMMUNICATION OF EARLY, UNPUBLISHED SCIENTIFIC DATA, ACCELERATING THE PACE OF RESEARCH. THE MEETING ALSO FURTHERS RESEARCH BY BUILDING PRODUCTIVE COLLABORATIONS-INCLUDING CROSS-DISCIPLINARY DIALOGUE, PARTNERSHIPS, INTEGRATION OF NEW RESEARCHERS AND DRUG COMPANIES, AND EDUCATIONAL OPPORTUNITIES FOR JUNIOR RESEARCHERS. THE MOST POWERFUL ACTIVITIES OF THE CONFERENCE HAPPEN WHEN THE FAMILY AND RESEARCHER CONFERENCES COME TOGETHER. FAMILIES HAVE DIRECT ACCESS TO THE LATEST INFORMATION ABOUT RESEARCH, AND RESEARCHERS HAVE AN OPPORTUNITY TO BUILD PERSONAL CONNECTIONS WITH THE PATIENTS WHO WILL BENEFIT FROM THEIR WORK.

SCHEDULE A
(Form 990 or 990-EZ)

Public Charity Status and Public Support

OMB No 1545-0047

2016

Open to Public Inspection

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.
▶ Attach to Form 990 or Form 990-EZ.
▶ Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

Department of the Treasury
Internal Revenue Service

Name of the organization
FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number
36-3320440

Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is (For lines 1 through 12, check only one box)

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

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
Total						

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
 (Complete only if you checked the box on line 5, 7, 8, or 9 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)2012	(b)2013	(c)2014	(d)2015	(e)2016	(f)Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant.")	4,596,877	4,639,671	4,716,073	5,374,986	6,321,242	25,648,849
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	4,596,877	4,639,671	4,716,073	5,374,986	6,321,242	25,648,849
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)						319,381
6 Public support. Subtract line 5 from line 4						25,329,468

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a)2012	(b)2013	(c)2014	(d)2015	(e)2016	(f)Total
7 Amounts from line 4	4,596,877	4,639,671	4,716,073	5,374,986	6,321,242	25,648,849
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	2,391	3,330	21,373	19,250	20,834	67,178
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)	589,565	556,430	605,696	1,111,599	2,032,374	4,895,664
11 Total support. Add lines 7 through 10						30,611,691
12 Gross receipts from related activities, etc. (see instructions)					12	1,205,020

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**

Section C. Computation of Public Support Percentage

14 Public support percentage for 2016 (line 6, column (f) divided by line 11, column (f))	14	82.740 %
15 Public support percentage for 2015 Schedule A, Part II, line 14	15	87.800 %

16a 33 1/3% support test—2016. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization

b 33 1/3% support test—2015. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization

17a 10%-facts-and-circumstances test—2016. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization

b 10%-facts-and-circumstances test—2015. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization

18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions

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

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ►		(a)2012	(b)2013	(c)2014	(d)2015	(e)2016	(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)2012	(b)2013	(c)2014	(d)2015	(e)2016	(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 VI.)						
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 ► <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15	Public support percentage for 2016 (line 8, column (f) divided by line 13, column (f))	15	
16	Public support percentage from 2015 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17	Investment income percentage for 2016 (line 10c, column (f) divided by line 13, column (f))	17	
18	Investment income percentage from 2015 Schedule A, Part III, line 17	18	
19a	33 1/3% support tests—2016. 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 ► <input type="checkbox"/>		
b	33 1/3% support tests—2015. 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 ► <input type="checkbox"/>		
20	Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ► <input type="checkbox"/>		

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

		Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
	1		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
	2		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer (b) and (c) below.		
	3a		
b	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the organization made the determination.		
	3b		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
	3c		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below.		
	4a		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
	4b		
c	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.		
	4c		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by amendment to the organizing document).		
	5a		
b	Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
	5b		
c	Substitutions only. Was the substitution the result of an event beyond the organization's control?		
	5c		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI .		
	6		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
	7		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
	8		
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI .		
	9a		
b	Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in Part VI .		
	9b		
c	Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI .		
	9c		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.		
	10a		
b	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)		
	10b		

Part IV Supporting Organizations (continued)

		Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?		
a	A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?		
b	A family member of a person described in (a) above?		
c	A 35% controlled entity of a person described in (a) or (b) above? <i>If "Yes" to a, b, or c, provide detail in Part VI</i>		

Section B. Type I Supporting Organizations

		Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
2	Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

		Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

		Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization (s) or (ii) serving on the governing body of a supported organization? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
3	By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions)		
a	<input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
b	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
c	<input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).		
2	Activities Test Answer (a) and (b) below.		
a	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
b	Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
3	Parent of Supported Organizations Answer (a) and (b) below.		
a	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>		
b	Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

- 1** Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970. **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A - Adjusted Net Income

	(A) Prior Year	(B) Current Year (optional)
1 Net short-term capital gain	1	
2 Recoveries of prior-year distributions	2	
3 Other gross income (see instructions)	3	
4 Add lines 1 through 3	4	
5 Depreciation and depletion	5	
6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6	
7 Other expenses (see instructions)	7	
8 Adjusted Net Income (subtract lines 5, 6 and 7 from line 4)	8	

Section B - Minimum Asset Amount

	(A) Prior Year	(B) Current Year (optional)
1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year)	1	
a Average monthly value of securities	1a	
b Average monthly cash balances	1b	
c Fair market value of other non-exempt-use assets	1c	
d Total (add lines 1a, 1b, and 1c)	1d	
e Discount claimed for blockage or other factors (explain in detail in Part VI)		
2 Acquisition indebtedness applicable to non-exempt use assets	2	
3 Subtract line 2 from line 1d	3	
4 Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions)	4	
5 Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6 Multiply line 5 by .035	6	
7 Recoveries of prior-year distributions	7	
8 Minimum Asset Amount (add line 7 to line 6)	8	

Section C - Distributable Amount

		Current Year
1 Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2 Enter 85% of line 1	2	
3 Minimum asset amount for prior year (from Section B, line 8, Column A)	3	
4 Enter greater of line 2 or line 3	4	
5 Income tax imposed in prior year	5	
6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6	
7 <input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D - Distributions	Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI) See instructions	
7 Total annual distributions. Add lines 1 through 6	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI) See instructions	
9 Distributable amount for 2016 from Section C, line 6	
10 Line 8 amount divided by Line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2016	(iii) Distributable Amount for 2016
1 Distributable amount for 2016 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2016 (reasonable cause required--see instructions)			
3 Excess distributions carryover, if any, to 2016			
a			
b			
c From 2013.			
d From 2014.			
e From 2015.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2016 distributable amount			
i Carryover from 2011 not applied (see instructions)			
j Remainder Subtract lines 3g, 3h, and 3i from 3f			
4 Distributions for 2016 from Section D, line 7			
a Applied to underdistributions of prior years			
b Applied to 2016 distributable amount			
c Remainder Subtract lines 4a and 4b from 4			
5 Remaining underdistributions for years prior to 2016, if any Subtract lines 3g and 4a from line 2 (if amount greater than zero, see instructions)			
6 Remaining underdistributions for 2016 Subtract lines 3h and 4b from line 1 (if amount greater than zero, see instructions)			
7 Excess distributions carryover to 2017. Add lines 3j and 4c			
8 Breakdown of line 7			
a			
b Excess from 2013.			
c Excess from 2014.			
d Excess from 2015.			
e Excess from 2016.			

Part VI Supplemental Information.

Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

SCHEDULE C
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

OMB No 1545-0047

2016
Open to Public Inspection

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

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

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

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

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-
2				
3				
4				
5				
6				

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
1a 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		
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?		

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

Yes 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 separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period

Calendar year (or fiscal year beginning in)	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(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 on 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?		No	
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?		No	
c	Media advertisements?		No	
d	Mailings to members, legislators, or the public?		No	
e	Publications, or published or broadcast statements?		No	
f	Grants to other organizations for lobbying purposes?		No	
g	Direct contact with legislators, their staffs, government officials, or a legislative body?		No	
h	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		No	
i	Other activities?	Yes		123,086
j	Total. Add lines 1c through 1i			123,086
2a	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		No	
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).	2a	
a	Current year	2b	
b	Carryover from last year	2c	
c	Total	3	
3	Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues		
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, lines 1 and 2 (see instructions), and Part II-B, line 1. Also, complete this part for any additional information.

Return Reference	Explanation
PART II-B, LINE 1	THE ORGANIZATION PAID DRINKER BIDDLE & REATH LLP, A LAW FIRM PROVIDING PROFESSIONAL LOBBYING SERVICES, FEES TO LOBBY FOR LEGISLATION THAT WOULD BENEFIT THE ORGANIZATION'S MISSION AND TO KEEP THE ORGANIZATION'S MANAGEMENT INFORMED ABOUT LEGISLATION THAT MAY AFFECT THE ORGANIZATION'S MISSION. OUR TEAM WORKS WITH PUBLIC POLICY EXPERTS AND ADVOCATES IN WASHINGTON AND IN THE STATE CAPITALS TO KEEP ABREAST OF DEVELOPMENTS IMPACTING THE CURE SMA COMMUNITY.

SCHEDULE D
(Form 990)

Supplemental Financial Statements

OMB No 1545-0047
2016
Open to Public Inspection

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

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

Department of the Treasury
Internal Revenue Service

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" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? Yes No

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? Yes No

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

1 Purpose(s) of conservation easements held by the organization (check all that apply)

Preservation of land for public use (e g , recreation or education) Preservation of an historically important land area

Protection of natural habitat Preservation of a certified historic structure

Preservation of open space

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year

	Held at the End of the Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register	2d

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ _____

4 Number of states where property subject to conservation easement is located ▶ _____

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? Yes No

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ▶ _____

7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ▶ \$ _____

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? Yes No

9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.
Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) Revenue included on Form 990, Part VIII, line 1 ▶ \$ _____

(ii) Assets included in Form 990, Part X ▶ \$ _____

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items

a Revenue included on Form 990, Part VIII, line 1 ▶ \$ _____

b Assets included in Form 990, Part X ▶ \$ _____

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" on 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 | |
| d Additions during the year | |
| e Distributions during the year | |
| f Ending balance | |
- 2a** Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? 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" on 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	854,008	741,466	620,515	436,946	220,438
b Contributions	116,736	112,008	109,608	181,698	214,976
c Net investment earnings, gains, and losses	87,854	534	11,343	1,871	1,532
d Grants or scholarships					
e Other expenditures for facilities and programs	26,285				
f Administrative expenses					
g End of year balance	1,032,313	854,008	741,466	620,515	436,946

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as
- a** Board designated or quasi-endowment ▶
 - b** Permanent endowment ▶
 - c** Temporarily restricted endowment ▶
- The percentages on 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 | 3a(i) | No |
| (ii) related organizations | 3a(ii) | No |
| b If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? | 3b | |
- 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' on 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		381,064	165,107	215,957
e Other				
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c)) . . . ▶				215,957

Part VII Investments—Other Securities. Complete if the organization answered 'Yes' on 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. (Column (b) must equal Form 990, Part X, col (B) line 12)		

Part VIII Investments—Program Related. Complete if the organization answered 'Yes' on 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. (Column (b) must equal Form 990, Part X, col (B) line 13)		

Part IX Other Assets. Complete if the organization answered 'Yes' on 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' on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

(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' on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	8,458,733
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12			
a	Net unrealized gains (losses) on investments	2a	72,220	
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII)	2d	519,938	
e	Add lines 2a through 2d			2e 592,158
3	Subtract line 2e from line 1			3 7,866,575
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	6,701	
b	Other (Describe in Part XIII)	4b		
c	Add lines 4a and 4b			4c 6,701
5	Total revenue Add lines 3 and 4c . (This must equal Form 990, Part I, line 12)			5 7,873,276

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

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	8,079,254
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	519,938	
e	Add lines 2a through 2d			2e 519,938
3	Subtract line 2e from line 1			3 7,559,316
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	6,701	
b	Other (Describe in Part XIII)	4b		
c	Add lines 4a and 4b			4c 6,701
5	Total expenses Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)			5 7,566,017

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.

Return Reference	Explanation
See Additional Data Table	

Part XIII Supplemental Information *(continued)*

Return Reference	Explanation

Additional Data

Software ID:

Software Version:

EIN: 36-3320440

Name: FAMILIES OF SPINAL MUSCULAR ATROPHY

Supplemental Information

Return Reference	Explanation
PART X, LINE 2	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

Supplemental Information

Return Reference	Explanation
PART XI, LINE 2D - OTHER ADJUSTMENTS	SPECIAL EVENT EXPENSE REPORTED ON PAGE 9, LINE 8B 496,065 COST OF SALES REPORTED ON PAGE 9, LINE 10B 23,873

Supplemental Information

Return Reference	Explanation
PART XII, LINE 2D - OTHER ADJUSTMENTS	SPECIAL EVENT EXPENSES REPORTED ON PAGE 9, LINE 8A 496,065 COST OF SALES REPORTED ON PAGE 9, LINE 10B 23,873

**SCHEDULE F
(Form 990)**

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

▶ Complete if the organization answered "Yes" to Form 990,
Part IV, line 14b, 15, or 16.
▶ Attach to Form 990. ▶ See separate instructions.
▶ Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2016

**Open to Public
Inspection**

Name of the organization
FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number
36-3320440

Part I **General Information on Activities Outside the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 14b.

- 1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?
 Yes No
- 2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States
- 3** Activities per Region (The following Part I, line 3 table can be duplicated if additional space is needed)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e.g., fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
(1)					
(2)					
(3)					
(4)					
(5)					
3a Sub-total	0	0			0
b Total from continuation sheets to Part I	0	0			0
c Totals (add lines 3a and 3b)	0	0			0

Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

Part IV Foreign Forms

- 1 Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U S Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* Yes No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U S Owner (see Instructions for Forms 3520 and 3520-A)* Yes No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U S Persons with Respect to Certain Foreign Corporations (see Instructions for Form 5471)* Yes No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)* Yes No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U S Persons with Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* Yes No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713)* Yes No

Part V Supplemental Information

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

Return Reference	Explanation
PART I, LINE 2	<p>CURE SMA HAS A COMMITTEE THAT EVALUATES ALL GRANT APPLICATIONS AND SELECTS GRANT BASED UPON THE QUALIFICATION OF THE INSTITUTION, RESEARCHER, THE RESEARCH PROJECT'S AND POTENTIAL APPLICABILITY TO SMA ONCE A GRANT HAS BEEN APPROVED, GRANTEEES ARE REQUIRED TO SUBMIT PROGRESS REPORTS BEFORE ADDITIONAL FUNDING IS AUTHORIZED EACH AWARD INCLUDES THE FOLLOWING TERMS -INSTITUTE (GRANTEE) SHALL PROVIDE SPONSOR (CURE SMA) WITH REPORTS OF THE WORK PERFORMED UNDER THIS AGREEMENT IN ACCORDANCE WITH THE FOLLOWING SCHEDULE 1)QUARTERLY WRITTEN PROGRESS REPORTS DUE WITHIN THIRTY (30) DAYS AFTER THE END OF EACH CALENDAR QUARTER 2)INSTITUTE SHALL SUBMIT TO SPONSOR A COMPREHENSIVE FINAL REPORT WITHIN NINETY (90) DAYS OF TERMINATION OR EXPIRATION OF THE RESEARCH PROJECT 3)INSTITUTE SHALL ALSO PROVIDE TO SPONSOR A SUCCINCT WRITTEN LAY REPORT OF ANY PUBLICATIONS RESULTING FROM RESEARCH PERFORMED UNDER THIS AGREEMENT CONTAINING A QUOTE FROM THE PRINCIPAL INVESTIGATOR</p>

Additional Data**Software ID:****Software Version:****EIN:** 36-3320440**Name:** FAMILIES OF SPINAL MUSCULAR ATROPHY**Form 990 Schedule F Part II - Grants or Entities Outside The United States**

(a) Name of organization	(b) IRS code section and EIN(if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	RESEARCH	30,000	WIRE TRANSFER			
		EUROPE (INCLUDING ICELAND & GREENLAND)	RESEARCH	70,000	WIRE TRANSFER			

Form 990 Schedule F Part II - Grants or Entities Outside The United States

(a) Name of organization	(b) IRS code section and EIN(if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE (INCLUDING ICELAND & GREENLAND)	RESEARCH	70,000	WIRE TRANSFER			
		EAST ASIA AND THE PACIFIC	RESEARCH	75,000	WIRE TRANSFER			

Form 990 Schedule F Part II - Grants or Entities Outside The United States

(a) Name of organization	(b) IRS code section and EIN(if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		SOUTH AMERICA	RESEARCH	140,000	WIRE TRANSFER			

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities

Complete if the organization answered "Yes" on Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a
▶ Attach to Form 990 or Form 990-EZ.
▶ Information about Schedule G (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2016

Open to Public Inspection

Name of the organization
FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number
36-3320440

Part I Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- a** Mail solicitations
 - b** Internet and email solicitations
 - c** Phone solicitations
 - d** In-person solicitations
 - e** Solicitation of non-government grants
 - f** Solicitation of government grants
 - g** Special fundraising events
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? Yes No
- b** If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
1 EPIPHANY PRODUCTIONS INC 104 HUME AVE ALEXANDRIA, VA 22301	SPECIAL EVENTS ASSISTANCE		No	279,500	24,868	254,632
2 EPIPHANY PRODUCTIONS INC 104 HUME AVE ALEXANDRIA, VA 22301	FUND RAISING CONSULTATIONS		No	0	2,500	-2,500
3						
4						
5						
6						
7						
8						
9						
10						
Total				279,500	27,368	252,132

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing

AL, AK, AZ, AR, CA, CO, CT, DE, FL, GA, HI, ID, IL, IN, IA, KS, KY, LA, ME, MD, MA, MI, MN, MS, MO, MT, NE, NV, NH, NJ, NM, NY, NC, ND, OH, OK, OR, PA, RI, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY, DC

Part II Fundraising Events. Complete if the organization answered "Yes" on 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.

Revenue		(a) Event #1	(b) Event #2	(c) Other events	(d)
		CONGRESSIONAL DINNER (event type)	GALA OF HOPE (event type)	120 (total number)	Total events (add col (a) through col (c))
1	Gross receipts	279,500	349,078	3,008,606	3,637,184
2	Less Contributions	148,680	57,100	2,928,597	3,134,377
3	Gross income (line 1 minus line 2)	130,820	291,978	80,009	502,807
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages	31,804	20,178		51,982
	8 Entertainment		62,270		62,270
	9 Other direct expenses	32,140	17,697	331,972	381,809
	10 Direct expense summary Add lines 4 through 9 in column (d) ▶				496,061
11 Net income summary Subtract line 10 from line 3, column (d) ▶				6,746	

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

Revenue		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
		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 conducts gaming activities _____

a Is the organization licensed to conduct 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 conduct 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 conducted 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 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).

Return Reference

Explanation

Schedule I (Form 990)

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

OMB No 1545-0047

2016

Open to Public Inspection

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

Attach to Form 990.

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

Department of the Treasury Internal Revenue Service

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

Table with 7 columns: (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, (g) Description of non-cash assistance, (h) Purpose of grant or assistance

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

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

(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
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					

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

Return Reference	Explanation
PART I, LINE 2	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 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
SCHEDULE I, PART II	CERTAIN GRANT PAYMENTS ARE MADE TO GRANTEEES 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 \$341,500

Additional Data

Software ID:
Software Version:
EIN: 36-3320440
Name: FAMILIES OF SPINAL MUSCULAR ATROPHY

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
TRUSTEES OF COLUMBIA UNIVERSITY IN NY 615 WEST 131ST STREET MAIL CODE 8749 NEW YORK, NY 10027	13-5598093	501(C)(3)	50,000				RESEARCH GRANT - PATIENT CARE
JOHNS HOPKINS UNIVERSITY 1101 E 33RD STREET STE C020 BALTIMORE, MD 21218	52-1317896	501(C)(3)	37,500				RESEARCH GRANT - DRUG DISCOVERY

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
OHIO STATE UNIVERSITY 901 WOODY HAYES DRIVE 2050 COLUMBUS, OH 43210	31-6025986	501(C)(3)	215,000				RESEARCH - BASIC
LURIE CHILDREN'S HOSPITAL PO BOX 269 CHICAGO, IL 60690	36-2170833	501(C)(3)	215,000				RESEARCH - BASIC

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
CURATORS OF THE UNIVERISTY OF MISSOURI 118 UNIVERSITY HALL COLUMBIA, MO 652113020	26-6440629	501(C)(3)	75,000				RESEARCH - BASIC

Schedule J
(Form 990)

Department of the Treasury
Internal Revenue Service

Compensation Information

OMB No 1545-0047

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.

2015
Open to Public Inspection

▶ Information about Schedule J (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
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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 on 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 in 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, 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 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 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 type="checkbox"/> Approval by the board or compensation committee									
4 During the year, did any person listed on 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	No								
b Participate in, or receive payment from, a supplemental nonqualified retirement plan?	4b	No								
c Participate in, or receive payment from, an equity-based compensation arrangement?	4c	No								
If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.										
Only 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.										
5 For persons listed on 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	No								
b Any related organization? If "Yes," on line 5a or 5b, describe in Part III.	5b	No								
6 For persons listed on 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	No								
b Any related organization? If "Yes," on line 6a or 6b, describe in Part III.	6b	No								
7 For persons listed on 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	No								
8 Were any amounts reported on 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	No								
9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?	9									

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 on 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 in column(B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
1 KENNETH HOBBY PRESIDENT	(i)	182,099 -----	0 -----	0 -----	0 -----	14,664 -----	196,763 -----	0 -----
	(ii)	0	0	0	0	0	0	0
2 JILL JARECKI RESEARCH DIRECTOR	(i)	171,689 -----	0 -----	0 -----	0 -----	628 -----	172,317 -----	0 -----
	(ii)	0	0	0	0	0	0	0

Part III **Supplemental Information**

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

Return Reference	Explanation
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**SCHEDULE M
(Form 990)**

Noncash Contributions

OMB No 1545-0047

2016

▶ **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**

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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				
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 ▶ (SEE PART II)	X	90	371,235	RETAIL 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**

30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 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?

	Yes	No
30a		No
31		No
32a		No

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?

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?

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.

Return Reference	Explanation
PART I, LINE 33	PAGE 1, LINE 25 THE AMOUNT ON LINE 25 INCLUDES DONATED RENTAL EQUIPMENT AND FOOD FOR SPECIAL EVENTS, DONATED EQUIPMENT, AND OTHER ITEMS

SCHEDULE O
(Form 990 or 990-EZ)Department of the Treasury
Internal Revenue Service

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

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

2016**Open to Public Inspection**

Employer identification number

36-3320440

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 11B	THE FINANCE COMMITTEE OF THE BOARD AND THE PRESIDENT PERFORM AN INITIAL REVIEW OF FORM 990 AFTER ACCEPTANCE OF FORM 990 BY THE FINANCE COMMITTEE AND THE PRESIDENT, FORM 990 IS EMAILED TO THE FULL BOARD FOR REVIEW AND APPROVAL BEFORE IT IS FILED

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 12C	MEMBERS OF THE BOARD OF DIRECTORS ARE REQUIRED TO SIGN AN ANNUAL STATEMENT DISCLOSING ANY POSSIBLE CONFLICTS OF INTEREST

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 15	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

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION C, LINE 19	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

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PAGE 9, PART VIII, LINE 11A	INCOME FROM NON-RECURRING LICENSING AGGEMENT

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PAGE 12, PART XII, QUESTION 2C	NO CHANGES WERE MADE TO THE AUDIT OVERSIGHT PROCESS FOR THE CURRENT YEAR