

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

▶ The organization may have to use a copy of this return to satisfy state reporting requirements.

A For the 2011 calendar year, or tax year beginning **JUL 1, 2011** and ending **JUN 30, 2012**

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization FAMILIES OF SPINAL MUSCULAR ATROPHY Doing Business As 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 country, and ZIP + 4 ELK GROVE VILLAGE, IL 60007 F Name and address of principal officer: KENNETH HOBBY SAME AS C ABOVE	D Employer identification number 36-3320440 E Telephone number 800-886-1762 G Gross receipts \$ 4,633,049. H(a) Is this a group return for affiliates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all affiliates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions) H(c) Group exemption number ▶
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c)() ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		
J Website: ▶ WWW.CURESMA.ORG		
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶		L Year of formation: 1984 M State of legal domicile: IL

Part I Summary

	1 Briefly describe the organization's mission or most significant activities: SEE SCHEDULE O			
Activities & Governance	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.			
	3 Number of voting members of the governing body (Part VI, line 1a)	3	15	
	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 2011 (Part V, line 2a)	5	18	
	6 Total number of volunteers (estimate if necessary)	6	4800	
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.	
	b Net unrelated business taxable income from Form 990-T, line 34	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year	
	9 Program service revenue (Part VIII, line 2g)	3,603,995.	4,241,909.	
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	837,510.	243,698.	
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	1,278.	2,108.	
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	32,879.	24,839.	
	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	4,475,662.	4,512,554.	
	14 Benefits paid to or for members (Part IX, column (A), line 4)	347,128.	1,027,417.	
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	0.	0.	
	16a Professional fundraising fees (Part IX, column (A), line 11e)	815,336.	990,573.	
	b Total fundraising expenses (Part IX, column (D), line 25) ▶ 981,416.	0.	0.	
Expenses	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	1,893,888.	1,709,615.	
	18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	3,056,352.	3,727,605.	
	19 Revenue less expenses. Subtract line 18 from line 12	1,419,310.	784,949.	
	Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year	End of Year
		21 Total liabilities (Part X, line 26)	1,679,333.	2,594,334.
22 Net assets or fund balances. Subtract line 21 from line 20		843,659.	973,670.	
		835,674.	1,620,664.	

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: KENNETH HOBBY, PRESIDENT Type or print name and title	Date: 11/12/12
Paid Preparer Use Only	Print/Type preparer's name: TANYA M. FERREIRO, CPA Preparer's signature: _____ Date: 11/13/12 Check if self-employed: <input type="checkbox"/> PTIN: P00450362 Firm's name: KAUFMAN, ROSSIN & CO., P.A. Firm's EIN: 59-1818353 Firm's address: 2699 S. BAYSHORE DRIVE MIAMI, FL 33133 Phone no.: 305-858-5600	

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

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: SEE SCHEDULE O

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

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

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.

4a (Code:) (Expenses \$ 856,230. including grants of \$) (Revenue \$ 23,755.) FAMILIES OF 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 \$50 MILLION IN RESEARCH AND BEEN INVOLVED IN FUNDING HALF OF ALL THE ONGOING NOVEL DRUG PROGRAMS FOR SMA. FAMILIES OF SMA IS A NONPROFIT 501(C)(3) ORGANIZATION, WITH 31 CHAPTERS AND 85,000 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

4b (Code:) (Expenses \$ 1,352,616. including grants of \$ 1,027,417.) (Revenue \$) FAMILIES OF SMA FUNDS AND DIRECTS THE LEADING SMA RESEARCH PROGRAMS TO ACCELERATE THE DISCOVERY OF AN EFFECTIVE TREATMENT AND CURE FOR SMA. TO REACH THIS END, OUR RESEARCH FUNDING PROGRAM HAS THREE DISTINCT PARTS: BASIC RESEARCH TO UNRAVEL THE BIOLOGY OF SMA; DRUG DISCOVERY TO MAKE SMA DRUGS; CLINICAL TRIAL INITIATIVES TO TEST NEW DRUGS IN HUMANS. OUR SUCCESSFUL RESULTS AND PROGRESS PROVIDES REAL HOPE FOR FAMILIES AND PATIENTS. FAMILIES OF SMA HAS FUNDED FIVE MULTI-CENTER CLINICAL TRIALS FOR EXISTING DRUGS THAT HAVE POTENTIAL FOR SMA. WE HAVE FUNDED FIVE LEADING NEW DRUG DEVELOPMENT PROGRAMS FOR THERAPIES SPECIALLY DESIGNED TO TREAT SMA. FSMA HAS INVESTED SIGNIFICANT RESOURCES INTO GROWING THE PIPELINE OF NEW THERAPIES FOR SMA, INCLUDING THE FIRST EVER CLINICAL TRIAL APPROVED FOR A NEW DRUG DESIGNED SPECIFICALLY FOR SMA.

4c (Code:) (Expenses \$ 352,685. including grants of \$) (Revenue \$ 243,698.) FAMILIES OF SMA HOSTS THE NATION'S LARGEST GATHERING OF THOSE AFFECTED BY SMA AND THE RESEARCHERS WORKING TOWARDS A CURE AT THE ANNUAL SMA CONFERENCE. EACH YEAR WE BRING TOGETHER FAMILIES AND RESEARCHERS FROM AROUND THE WORLD TO SHARE IDEAS AND HOPE FOR THE FUTURE. WE COORDINATED THE LARGEST GATHERING OF THE SMA COMMUNITY EVER THIS YEAR WITH 1,500 ATTENDEES.

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

4e Total program service expenses 2,561,531.

Part IV Checklist of Required Schedules

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

Part IV Checklist of Required Schedules (continued)

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

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

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response to any question in this Part V

Input box for Schedule O response

Table with columns for question number, description, and Yes/No boxes. Includes questions 1a-14b regarding Form 1096, Form W-2G, employee reporting, foreign accounts, prohibited transactions, and charitable trusts.

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

Check if Schedule O contains a response to any question in this Part VI **X**

Section A. Governing Body and Management

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year 15 If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O.		
b	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?		X
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?		X
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		X
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		X
6	Did the organization have members or stockholders?		X
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?		X
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a	The governing body?	X	
b	Each committee with authority to act on behalf of the governing body?	X	
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		X

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

		Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	X	
b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	X	
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	X	
b	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	X	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	X	
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	X	
13	Did the organization have a written whistleblower policy?	X	
14	Did the organization have a written document retention and destruction policy?	X	
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?		
a	The organization's CEO, Executive Director, or top management official	X	
b	Other officers or key employees of the organization	X	
	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?		X
b	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, MA, MI**
- 18** Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
 Own website Another's website Upon request
- 19** Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
- 20** State the name, physical address, and telephone number of the person who possesses the books and records of the organization: **KENNETH HOBBY - 800-886-1762**
925 BUSSE ROAD, ELK GROVE VILLAGE, IL 60007

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

Check if Schedule O contains a response to any question in this Part VII

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

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

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

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

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

(A) Name and Title	(B) Average hours per week (describe hours for related organizations in Schedule O)	(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) PAULA BARRETT BOARD CHAIR	12.00	X		X				0.	0.	0.
(2) ADI RAPPOPORT DIRECTOR	6.00	X						0.	0.	0.
(3) NATALIE GIBBS DIRECTOR	2.00	X						0.	0.	0.
(4) JEFF ANDRADE DIRECTOR	2.00	X						0.	0.	0.
(5) ROCCO ARIZZI DIRECTOR	2.00	X						0.	0.	0.
(6) AMY MARQUEZ DIRECTOR	2.00	X						0.	0.	0.
(7) MARY MCHALE DIRECTOR	2.00	X						0.	0.	0.
(8) DOUGLAS ERWIN DIRECTOR	2.00	X						0.	0.	0.
(9) ROBERT LOCKWOOD DIRECTOR	2.00	X						0.	0.	0.
(10) STEVE RAGLAND SECRETARY	2.00	X		X				0.	0.	0.
(11) MELISSA MILINOVICH DIRECTOR	2.00	X						0.	0.	0.
(12) RICHARD RUBENSTEIN TREASURER	2.00	X		X				0.	0.	0.
(13) JUSTIN KUESTER DIRECTOR	2.00	X						0.	0.	0.
(14) JAMES GAUDREAU DIRECTOR	2.00	X						0.	0.	0.
(15) BARB TRAINOR DIRECTOR	2.00	X						0.	0.	0.
(16) BRAD NUNEMAKER DIRECTOR	2.00	X						0.	0.	0.
(17) KENNETH HOBBY PRESIDENT	70.00			X	X			148,700.	0.	0.

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

(A) Name and title	(B) Average hours per week (describe hours for related organizations in Schedule O)	(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) JILL JARECKI RESEARCH DIRECTOR	30.00					X		112,981.	0.	0.
(19) NANCY MCINROY DEVELOPMENT DIRECTOR	40.00					X		130,231.	0.	4,000.
1b Sub-total								391,912.	0.	4,000.
c Total from continuation sheets to Part VII, Section A								0.	0.	0.
d Total (add lines 1b and 1c)								391,912.	0.	4,000.

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>		X
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>		X
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>		X

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
NONE		

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 **0**

Part VIII Statement of Revenue

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514	
Contributions, Gifts, Grants and Other Similar Amounts	1 a Federated campaigns	1a					
	b Membership dues	1b	1,341.				
	c Fundraising events	1c	2907286.				
	d Related organizations	1d					
	e Government grants (contributions)	1e	27,500.				
	f All other contributions, gifts, grants, and similar amounts not included above	1f	1305782.				
	g Noncash contributions included in lines 1a-1f: \$		688.				
	h Total. Add lines 1a-1f		4241909.				
	Program Service Revenue	2 a ANNUAL CONFERENCE	Business Code 900099	243,698.	243,698.		
b							
c							
d							
e							
f All other program service revenue							
g Total. Add lines 2a-2f			243,698.				
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		2,193.			2,193.	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6 a Gross rents	(i) Real					
		(ii) Personal					
		b Less: rental expenses					
		c Rental income or (loss)					
	d Net rental income or (loss)						
	7 a Gross amount from sales of assets other than inventory	(i) Securities					
		(ii) Other					
		b Less: cost or other basis and sales expenses		2,829.			
		c Gain or (loss)		-85.			
	d Net gain or (loss)		-85.			-85.	
	8 a Gross income from fundraising events (not including \$ 2,907,286. of contributions reported on line 1c). See Part IV, line 18	a	118750.				
		b Less: direct expenses	b	117666.			
c Net income or (loss) from fundraising events			1,084.			1,084.	
9 a Gross income from gaming activities. See Part IV, line 19	a						
	b Less: direct expenses	b					
	c Net income or (loss) from gaming activities						
10 a Gross sales of inventory, less returns and allowances	a						
	b Less: cost of goods sold	b					
	c Net income or (loss) from sales of inventory						
Miscellaneous Revenue		Business Code					
11 a MISCELLANEOUS		900099	23,755.	23,755.			
	b						
	c						
	d All other revenue						
	e Total. Add lines 11a-11d		23,755.				
12 Total revenue. See instructions.			4512554.	267,453.	0.	3,192.	

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) but are not required to complete columns (B), (C), and (D).

Check if Schedule O contains a response to any question in this Part IX

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the United States. See Part IV, line 21	1,027,417.	1,027,417.		
2 Grants and other assistance to individuals in the United States. See Part IV, line 22				
3 Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	404,164.	244,532.	31,518.	128,114.
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	496,738.	241,699.	50,176.	204,863.
8 Pension plan accruals and contributions (include section 401(k) and section 403(b) employer contributions)				
9 Other employee benefits	18,782.	14,340.	1,857.	2,585.
10 Payroll taxes	70,889.	33,514.	5,437.	31,938.
11 Fees for services (non-employees):				
a Management				
b Legal	30,598.	30,098.		500.
c Accounting	40,379.	27,566.	6,083.	6,730.
d Lobbying	49,441.	47,626.	1,815.	
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other	75,856.	71,946.	2,102.	1,808.
12 Advertising and promotion	70,324.	49,532.	9,500.	11,292.
13 Office expenses	268,918.	179,096.	22,779.	67,043.
14 Information technology	63,151.	44,094.	6,386.	12,671.
15 Royalties				
16 Occupancy	81,956.	54,637.	13,660.	13,659.
17 Travel	82,292.	24,767.	23,932.	33,593.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	355,867.	352,685.		3,182.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	20,999.	17,073.	1,963.	1,963.
23 Insurance	13,363.	8,909.	2,227.	2,227.
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	448,975.	38,159.	1,246.	409,570.
b PATIENT SERVICES	52,950.	45,334.		7,616.
c MERCHANDISE	34,151.			34,151.
d MISCELLANEOUS	20,395.	8,507.	3,977.	7,911.
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	3,727,605.	2,561,531.	184,658.	981,416.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

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

Part X Balance Sheet

		(A) Beginning of year		(B) End of year	
Assets	1 Cash - non-interest-bearing	1,229,433.	1	1,470,911.	
	2 Savings and temporary cash investments	195,283.	2	739,867.	
	3 Pledges and grants receivable, net	109,687.	3	222,704.	
	4 Accounts receivable, net		4	11,015.	
	5 Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5		
	6 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)		6		
	7 Notes and loans receivable, net		7		
	8 Inventories for sale or use		8		
	9 Prepaid expenses and deferred charges	29,345.	9	11,755.	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 350,689.			
	b Less: accumulated depreciation	10b 255,594.	70,710.	10c 95,095.	
	11 Investments - publicly traded securities	2,617.	11	729.	
	12 Investments - other securities. See Part IV, line 11	36,461.	12	36,461.	
	13 Investments - program-related. See Part IV, line 11		13		
	14 Intangible assets		14		
	15 Other assets. See Part IV, line 11	5,797.	15	5,797.	
16 Total assets. Add lines 1 through 15 (must equal line 34)	1,679,333.	16	2,594,334.		
Liabilities	17 Accounts payable and accrued expenses	448,297.	17	428,023.	
	18 Grants payable	395,362.	18	545,647.	
	19 Deferred revenue		19		
	20 Tax-exempt bond liabilities		20		
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21		
	22 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	843,659.	26	973,670.	
Net Assets or Fund Balances	Organizations that follow SFAS 117, check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.				
	27 Unrestricted net assets	745,998.	27	1,257,728.	
	28 Temporarily restricted net assets	89,676.	28	142,498.	
	29 Permanently restricted net assets		29	220,438.	
	Organizations that do not follow SFAS 117, check here <input type="checkbox"/> and complete lines 30 through 34.				
	30 Capital stock or trust principal, or current funds		30		
	31 Paid-in or capital surplus, or land, building, or equipment fund		31		
	32 Retained earnings, endowment, accumulated income, or other funds		32		
	33 Total net assets or fund balances	835,674.	33	1,620,664.	
34 Total liabilities and net assets/fund balances	1,679,333.	34	2,594,334.		

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response to any question in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1	4,512,554.
2	Total expenses (must equal Part IX, column (A), line 25)	2	3,727,605.
3	Revenue less expenses. Subtract line 2 from line 1	3	784,949.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	835,674.
5	Other changes in net assets or fund balances (explain in Schedule O)	5	41.
6	Net assets or fund balances at end of year. Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))	6	1,620,664.

Part XII Financial Statements and Reporting

Check if Schedule O contains a response to any question in this Part XII

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

Form 990 (2011)

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No. 1545-0047

2011

Open to Public Inspection

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 11, 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.)
- 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 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.)
- 10 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4).**
- 11 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 that describes the type of supporting organization and complete lines 11e through 11h.
 - a Type I b Type II c Type III - Functionally integrated d Type III - Other
- e By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f If the organization received a written determination from the IRS that it is a Type I, Type II, or Type III supporting organization, check this box
- g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

	Yes	No
(i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?	11g(i)	
(ii) A family member of a person described in (i) above?	11g(ii)	
(iii) A 35% controlled entity of a person described in (i) or (ii) above?	11g(iii)	
- h Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section (see instructions))	(iv) Is the organization in col. (i) listed in your governing document?		(v) Did you notify the organization in col. (i) of your support?		(vi) Is the organization in col. (i) organized in the U.S.?		(vii) Amount of support
			Yes	No	Yes	No	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, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3						
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public support. Subtract line 5 from line 4.						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
7 Amounts from line 4						
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
11 Total support. Add lines 7 through 10						
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2011 (line 6, column (f) divided by line 11, column (f))	14	%
15 Public support percentage from 2010 Schedule A, Part II, line 14	15	%
16a 33 1/3% support test - 2011. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		<input type="checkbox"/>
b 33 1/3% support test - 2010. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		<input type="checkbox"/>
17a 10% -facts-and-circumstances test - 2011. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization		<input type="checkbox"/>
b 10% -facts-and-circumstances test - 2010. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization		<input type="checkbox"/>
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions		<input type="checkbox"/>

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

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

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	2,386,340.	3,759,212.	3,553,474.	3,603,995.	4,266,911.	17,569,932.
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	67,486.	101,901.	2,276.	23,488.	23,755.	218,906.
3 Gross receipts from activities that are not an unrelated trade or business under section 513			895,824.	837,510.	243,698.	1,977,032.
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	2,453,826.	3,861,113.	4,451,574.	4,464,993.	4,534,364.	19,765,870.
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						0.
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						0.
c Add lines 7a and 7b						0.
8 Public support (Subtract line 7c from line 6.)						19,765,870.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
9 Amounts from line 6	2,453,826.	3,861,113.	4,451,574.	4,464,993.	4,534,364.	19,765,870.
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	34,393.	6,111.	2,892.	1,278.	2,193.	46,867.
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b	34,393.	6,111.	2,892.	1,278.	2,193.	46,867.
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)	2,521,045.	468,656.	53,666.	80,770.	93,748.	3,217,885.
13 Total support (Add lines 9, 10c, 11, and 12.)	5,009,264.	4,335,880.	4,508,132.	4,547,041.	4,630,305.	23,030,622.

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

Section C. Computation of Public Support Percentage

15 Public support percentage for 2011 (line 8, column (f) divided by line 13, column (f))	15	85.82 %
16 Public support percentage from 2010 Schedule A, Part III, line 15	16	74.17 %

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2011 (line 10c, column (f) divided by line 13, column (f))	17	.20 %
18 Investment income percentage from 2010 Schedule A, Part III, line 17	18	.45 %

19a 33 1/3% support tests - 2011. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

b 33 1/3% support tests - 2010. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

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

SCHEDULE C
(Form 990 or 990-EZ)

Political Campaign and Lobbying Activities

OMB No. 1545-0047

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

2011

Department of the Treasury
Internal Revenue Service

▶ **Complete if the organization is described below.** ▶ **Attach to Form 990 or Form 990-EZ.**

Open to Public Inspection

▶ **See separate instructions.**

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

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

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

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

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

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

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

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

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

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

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

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

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

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

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule C (Form 990 or 990-EZ) 2011

LHA

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

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

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

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

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column(e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

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

For each "Yes" response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.	(a)		(b)
	Yes	No	Amount
1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?		X	
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? ..		X	
c Media advertisements?		X	
d Mailings to members, legislators, or the public?		X	
e Publications, or published or broadcast statements?		X	
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?		X	
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		X	
i Other activities?	X		49,440.
j Total. Add lines 1c through 1i			49,440.
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		X	
b If "Yes," enter the amount of any tax incurred under section 4912			
c If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

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

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

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

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

Part IV Supplemental Information

Complete this part to provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A; and Part II-B, line 1. Also, complete this part for any additional information.

PART II-B, LINE 1, LOBBYING ACTIVITIES:

THE ORGANIZATION PAID WASHINGTON STRATEGIC CONSULTING, INC, A PROFESSIONAL LOBBYING FIRM, FEES TOTALING \$49,440 TO LOBBY FOR LEGISLATION THAT BENEFITS THE ORGANIZATION'S MISSION AND TO KEEP THE ORGANIZATION'S MANAGEMENT INFORMED ABOUT LEGISLATION THAT MAY AFFECT THE ORGANIZATION'S MISSION.

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

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

Attach to Form 990. See separate instructions.

OMB No. 1545-0047

2011

Open to Public Inspection

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

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

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

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

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

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

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

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

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

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

- 1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No
- b If "Yes," explain the arrangement in Part XIV and complete the following table:

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

- 2a Did the organization include an amount on Form 990, Part X, line 21? Yes No
- b If "Yes," explain the arrangement in Part XIV.

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	0.				
b Contributions	220,438.				
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance	220,438.				

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment _____ %
 - b Permanent endowment 100.00 %
 - c Temporarily restricted endowment _____ %
- The percentages in lines 2a, 2b, and 2c should equal 100%.

- 3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- | | Yes | No |
|---|-----|----|
| (i) unrelated organizations | | X |
| (ii) related organizations | | X |
| b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R? | | |

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

Part VI Land, Buildings, and Equipment. 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		350,689.	255,594.	95,095.
e Other				
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				95,095.

Part VII Investments - Other Securities. See Form 990, Part X, line 12.

Table with 3 columns: (a) Description of security or category, (b) Book value, (c) Method of valuation. Rows include Financial derivatives, Closely-held equity interests, and Other (A-I).

Part VIII Investments - Program Related. See Form 990, Part X, line 13.

Table with 3 columns: (a) Description of investment type, (b) Book value, (c) Method of valuation. Rows numbered 1 through 10.

Part IX Other Assets. See Form 990, Part X, line 15.

Table with 2 columns: (a) Description, (b) Book value. Rows numbered 1 through 10.

Part X Other Liabilities. See Form 990, Part X, line 25.

Table with 2 columns: (a) Description of liability, (b) Book value. Row 1 includes Federal income taxes, followed by rows 2-11.

FIN 48 (ASC 740) Footnote. In Part XIV, 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).

Part XI Reconciliation of Change in Net Assets from Form 990 to Audited Financial Statements

1	Total revenue (Form 990, Part VIII, column (A), line 12)	1	4,512,554.
2	Total expenses (Form 990, Part IX, column (A), line 25)	2	3,727,605.
3	Excess or (deficit) for the year. Subtract line 2 from line 1	3	784,949.
4	Net unrealized gains (losses) on investments	4	41.
5	Donated services and use of facilities	5	
6	Investment expenses	6	
7	Prior period adjustments	7	
8	Other (Describe in Part XIV.)	8	
9	Total adjustments (net). Add lines 4 through 8	9	41.
10	Excess or (deficit) for the year per audited financial statements. Combine lines 3 and 9	10	784,990.

Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

1	Total revenue, gains, and other support per audited financial statements	1	4,630,261.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a	Net unrealized gains on investments	2a	41.
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIV.)	2d	117,666.
e	Add lines 2a through 2d	2e	117,707.
3	Subtract line 2e from line 1	3	4,512,554.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIV.)	4b	
c	Add lines 4a and 4b	4c	0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5	4,512,554.

Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return

1	Total expenses and losses per audited financial statements	1	3,845,271.
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 XIV.)	2d	117,666.
e	Add lines 2a through 2d	2e	117,666.
3	Subtract line 2e from line 1	3	3,727,605.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIV.)	4b	
c	Add lines 4a and 4b	4c	0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	5	3,727,605.

Part XIV Supplemental Information

Complete this part to 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, line 8; Part XII, lines 2d and 4b; and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

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.

Part XIV Supplemental Information (continued)

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

PART XII, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENT EXPENSES 117,666.

PART XIII, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENT EXPENSES 117,666.

Supplemental Information Regarding Fundraising or Gaming Activities

2011

Department of the Treasury
Internal Revenue Service

**Complete if the organization answered "Yes" to 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. ▶ See separate instructions.**

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" to 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

2 a 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			
Total				▶		

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.

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

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events	
		WALK & ROLL	DINNERS / GALAS	262	(add col. (a) through col. (c))	
		(event type)	(event type)	(total number)		
Revenue	1	Gross receipts	1,212,777.	557,302.	1,255,957.	3,026,036.
	2	Less: Charitable contributions	1,212,777.	438,552.	1,255,957.	2,907,286.
	3	Gross income (line 1 minus line 2)		118,750.		118,750.
Direct Expenses	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
	7	Food and beverages				
	8	Entertainment				
	9	Other direct expenses		117,666.		117,666.
	10	Direct expense summary. Add lines 4 through 9 in column (d)				(117,666)
	11	Net income summary. Combine line 3, column (d), and line 10				1,084.

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

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

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

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

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

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

Name ▶ _____

Address ▶ _____

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

Name ▶ _____

Address ▶ _____

16 Gaming manager information:

Name ▶ _____

Gaming manager compensation ▶ \$ _____

Description of services provided ▶ _____

- Director/officer Employee Independent contractor

17 Mandatory distributions:

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

Part IV **Supplemental Information.** Complete this part to 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).

FORM 990, SCHEDULE D, PART II, FUNDRAISING EVENTS

EXPLANATION OF SPECIAL EVENTS

FAMILIES OF SMA HAS MULTIPLE CHAPTERS IN 22 STATES WHOSE PURPOSE IS TO RAISE FUNDS FOR THE ORGANIZATION. THE AMOUNTS LISTED IN COLUMNS (A) AND (C) ARE SUMMARY AMOUNTS FOR MULTIPLE SIMILAR EVENTS HELD THROUGHOUT THE COUNTRY. AMOUNTS LISTED IN COLUMN (C) ARE FOR A VARIETY OF EVENTS HELD BY CHAPTERS THROUGHOUT THE COUNTRY.

COLUMN (A): PARTICIPANTS IN THE WALK AND ROLL EVENTS RECEIVE NO DIRECT

Part IV Supplemental Information (continued)

BENEFITS OTHER THAN A TEE-SHIRT AND ACCESS TO BEVERAGES ALONG THE RACE PATH AND AT THE END OF THE RACE PATH.

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

**SCHEDULE I
(Form 990)**

Department of the Treasury
Internal Revenue Service

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

**Complete if the organization answered "Yes" to Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990.**

OMB No. 1545-0047

2011

**Open to Public
Inspection**

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

Part I General Information on Grants and Assistance

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

Part II Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. Part II can be duplicated if additional space is needed

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
THE OHIO STATE UNIVERSITY RESEARCH FOUNDATION - 1960 KENNY ROAD - COLUMBUS, OH 43210	31-6025986	501(C)(3)	70,000.	0.			VALIDATION OF SMA BIOMARKERS IN VALIANT SUBJECTS
TRUSTEES OF INDIANA UNIVERSITY 620 UNION DRIVE, RM 518 INDIANAPOLIS, IN 46202	13-5598093	501(C)(3)	77,898.	0.			IDENTIFY, RETAIN AND RECRUIT SMA PATIENTS, TRACK RESEARCH AND EXPAND AWARENESS AND USE OF
RUTGERS, THE STATE UNIVERSITY OF NEW JERSEY - 3 RUTGERS PLAZA, 2ND FLOOR - NEW BRUNSWICK, NJ 08901	22-6001086	501(C)(3)	60,000.	0.			STUDY OF THE CECHANISM OF DRUG ACTION IN SMN2 UPREGULATION
STANFORD UNIVERSITY 340 PANAMA STREET STANFORD, CA 94305	94-1156365	501(C)(3)	0.	0.			CHARACTERIZATION OF RNA 'S WITHIN SMN RNA GRANULES IN MOTOR NEURONS
THE TRUSTEES OF COLUMBIA UNIVERSITY - 630 W. 168TH ST, BOX 49 - NEW YORK, NY 10032	13-5598093	501(C)(3)	220,000.	0.			RESEARCH OF SMA AS A PROGRESSIVE SYNAPTIC DISEASE
EMORY UNIVERSITY 1599 CLIFTON ROAD, 4TH FL ATLANTA, GA 30329	58-0566256	501(C)(3)	52,500.	0.			TO RESEARCH THE EFFECTS OF SMN DEFICIENCY ON MRNA

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **12.**
- 3** Enter total number of other organizations listed in the line 1 table

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule I (Form 990) (2011)

SEE PART IV FOR COLUMN (H) DESCRIPTIONS

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

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
THE UNIVERSITY OF SOUTHERN CALIFORNIA - 837 DOWNEY WAY - LOS ANGELES, CA 96150	95-6006143	501(C)(3)	17,500.	0.			RESEARCH OF NOVEL NEUROMUSCULAR PREPARATIONS
CALIFORNIA INSTITUTE OF BIOMEDICAL RESEARCH - 10931 NORTH TORREY PINES ROAD - LA JOLLA, CA 92037	95-6047739	501(C)(3)	120,000.	0.			RESEARCH OPTIMIZATION OF SMALL MOLECULES THAT INC. SMN2
THE SCRIPPS RESEARCH INSTITUTE 10550 NORTH TORREY PINES ROAD LA JOLLA, CA 92037	33-0435954	170(B)(1)	24,060.	0.			RESEARCH OF OPTIMIZATION OF SMALL MOLECULES THAT INC. SMN2
THE RESEARCH INSTITUTE AT NATIONWIDE CHILDREN'S HOSPITAL - 700 CHILDREN'S DRIVE - COLUMBUS, OH 43205	31-1036372	501(C)(3)	75,000.	0.			IND ENABLINGS STUDIES FOR A CNS DELIVERED GENE THERAPY
CHARLES RIVER LABORATORIES, INC PO BOX 27812 NEW YORK, NY 10087	06-1397316		15,280.	0.			TOXICITY STUDY OF HUMAN EMBRYONIC STEM CELLS
BOARD OF REGENTS UNIVERSITY OF WISCONSIN - 21 NORTH PARK ST, STE 6401 - MADISON, WI 53715	39-1805963	170(C)(1)	30,000.	0.			DEVELOPMENT OF THE PROTOCOL PROJECT CURE SMA
BOOZ ALLEN HAMILTON 1101 WOOTTON PARKWAY ROCKVILLE, MD 20852	36-2513626		34,920.	0.			TO PROVIDE PROJECT MANAGEMENT SUPPORT AND A DATA REPOSITORY PLAN
ARIZONA BOARD OF REGENTS 2020 N. CENTRAL AVENUE, SUITE 230 PHOENIX, AZ 85004	86-0196696	501(C)(3)	19,125.	0.			RESEARCH FUNDING

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

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

Part IV **Supplemental Information.** Complete this part to provide the information required in Part I, line 2, and any other additional information.

SCHEDULE I, 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.

Part IV Supplemental Information

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

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

PART II, LINE 1, COLUMN (H):

NAME OF ORGANIZATION OR GOVERNMENT: TRUSTEES OF INDIANA UNIVERSITY

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

SCHEDULE I, PART II

GRANTS AND OTHER ASSISTANCE TO ORGANIZATIONS IN THE UNITED STATES:

THE RESEARCH GRANTS REPORTED ON SCHEDULE I, PART II REFLECT CASH PAYMENTS MADE TO THE RECIPIENTS FOR THE YEAR ENDED JUNE 30, 2012 INCLUDING AMOUNTS REPORTED AS PAYABLE AT THE BEGINNING OF THE YEAR. AMOUNTS ACCRUED BUT UNPAID AS OF JUNE 30, 2012 ARE SHOWN AS GRANTS PAYABLE ON FORM 990, PAGE 11.

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 \$755,000.

**SCHEDULE J
(Form 990)**

Department of the Treasury
Internal Revenue Service

Compensation Information

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

▶ Complete if the organization answered "Yes" to Form 990, Part IV, line 23.

▶ Attach to Form 990. ▶ See separate instructions.

OMB No. 1545-0047

2011

Open to Public Inspection

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

Part I Questions Regarding Compensation

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

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

Schedule J (Form 990) 2011

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

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

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

(A) Name		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation reported as deferred in prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
1	(i)							
	(ii)							
2	(i)							
	(ii)							
3	(i)							
	(ii)							
4	(i)							
	(ii)							
5	(i)							
	(ii)							
6	(i)							
	(ii)							
7	(i)							
	(ii)							
8	(i)							
	(ii)							
9	(i)							
	(ii)							
10	(i)							
	(ii)							
11	(i)							
	(ii)							
12	(i)							
	(ii)							
13	(i)							
	(ii)							
14	(i)							
	(ii)							
15	(i)							
	(ii)							
16	(i)							
	(ii)							

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

OMB No. 1545-0047

2011

Open to Public
Inspection

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

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

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

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

FAMILIES OF SPINAL MUSCULAR ATROPHY (SMA) IS DEDICATED TO CREATING A
TREATMENT AND CURE FOR SPINAL MUSCULAR ATROPHY BY

1. FUNDING AND ADVANCING A COMPREHENSIVE RESEARCH PROGRAM
2. SUPPORTING SMA FAMILIES THROUGH NETWORKING, INFORMATION AND SERVICES
3. IMPROVING CARE FOR ALL SMA PATIENTS
4. EDUCATING HEALTH PROFESSIONALS AND THE PUBLIC ABOUT SMA
5. ENLISTING GOVERNMENT SUPPORT FOR SMA
6. EMBRACING ALL TOUCHED BY SMA IN A CARING COMMUNITY

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

PROFESSIONALS AND THE PUBLIC ABOUT SMA; ENLISTING GOVERNMENT SUPPORT
FOR SMA; EMBRACING ALL TOUCHED BY SMA IN A CARING COMMUNITY.

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

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

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

MEMBERS OF THE BOARD OF DIRECTORS ARE REQUIRED TO SIGN AN ANNUAL STATEMENT

Name of the organization FAMILIES OF SPINAL MUSCULAR ATROPHY	Employer identification number 36-3320440
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DISCLOSING ANY POSSIBLE CONFLICTS OF INTEREST.

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.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:

AL, AZ, CA, CO, CT, FL, IA, IL, KS, LA, MA, MI, MD, MN, NJ, NY, OH, PA, TN, TX, WA, WI, AK

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.

FORM 990, PART XI, LINE 5, CHANGES IN NET ASSETS:

NET UNREALIZED GAINS ON INVESTMENTS: 41.

FORM 990, PAGE 12, PART XII, QUESTION 2C:

NO CHANGES WERE MADE TO THE AUDIT OVERSIGHT PROCESS FOR THE CURRENT YEAR.