

# 2012 Electronic Filing Information (990/PF/EZ/1120-POL)

## Signature Method

Option (1) - Using Practitioner PIN. Use Section (A) below.

Date return prepared

1/10/2014

Option (2) - Scanned 8453-EO.

**PIN Information** Enter information below

(A) Practitioner PIN:			
	PIN (5 Digits)	TP entered	ERO entered
Taxpayer PIN:	45195	<input type="checkbox"/>	<input checked="" type="checkbox"/>
ERO PIN:	21352		

If the ERO entered taxpayer PIN, you must fill out the 8879-EO (IRS e-file Signature Authorization Form).

## EFIN

Enter your 6-digit EFIN number. You can enter EFINs in the Paid Preparer Table (press F3 to open.)

EFIN: 759614

## Submission ID

The Submission ID for this return will be computed automatically when you create the e-file and will be displayed here.

Submission ID: 75961420140103914757

## Name Control

(See instructions on the 'Name Control' tab)

AMER

## Organization Information

Organization name AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.		Employer identification no. 75-2245195	
Street address P.O. BOX 1586		Daytime phone (903) 236-7079	
Address continuation		In care of name	
City LONGVIEW	State TX	ZIP code 75606-1586	Foreign country
Email address		Foreign phone number	
Officer name Annie Chapman		Title treasurer	Date return signed 01/10/2014
Email address		Phone	Authorize third party check ("X") here: <input checked="" type="checkbox"/>

## ERO

(Enter data in the Preparer Manager)

ERO's name Nan Mitchell		Check if self-employed <input checked="" type="checkbox"/>	ERO's SSN or PTIN P00142493	
Firm's name Nan S. Mitchell, CPA		Email address		ERO's EIN 75-1647559
Address 10515 FM 349		Phone (903) 643-9476		
City Longview	State TX	ZIP code 75603	Foreign country	Foreign phone number

## Paid Preparer

(Enter data in the Preparer Manager)

Paid preparer's name Nan Mitchell		Non-paid prep type	Check if self-employed <input checked="" type="checkbox"/>	Preparer's SSN or PTIN P00142493	
Firm's name Nan S. Mitchell, CPA		Email address		EIN 75-1647559	
Address 10515 FM 349		Phone (903) 643-9476			
City Longview	State TX	ZIP code 75603	Foreign country	Foreign phone number	

**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)

Department of the Treasury  
Internal Revenue Service

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

<b>A</b> For the 2012 calendar year, or tax year beginning <u>6/1/2012</u> , and ending <u>5/31/2013</u>	
<b>B</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	<b>C</b> Name of organization <u>AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.</u>
	Doing Business As <u>American Syringomyelia &amp; Chiari Alliance Project, Inc.</u>
	Number and street (or P.O. box if mail is not delivered to street address) Room/suite <u>P.O. BOX 1586</u>
	City, town or post office, state, and ZIP code <u>LONGVIEW TX 75606-1586</u>
	<b>F</b> Name and address of principal officer: <u>Patrice Schaublin 700 Admiral Lane, Durham, NC 27705</u>
<b>D</b> Employer identification number <u>75-2245195</u>	
<b>E</b> Telephone number <u>(903) 236-7079</u>	
<b>G</b> Gross receipts \$ <u>456,233</u>	
<b>H(a)</b> Is this a group return for affiliates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	
<b>H(b)</b> Are all affiliates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions)	
<b>I</b> 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	
<b>J</b> Website: ▶ <u>www.asap.org</u>	
<b>H(c)</b> Group exemption number ▶	
<b>K</b> Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶	<b>L</b> Year of formation: <u>1988</u>
<b>M</b> State of legal domicile: <u>TX</u>	

**Part I Summary**

<b>Activities &amp; Governance</b>	<b>1</b> Briefly describe the organization's mission or most significant activities: <u>To provide support for persons affected by Syringomyelia and Chiari Malformation while raising funds to conduct research for a cure.</u>	
	<b>2</b> Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.	
<b>3</b> Number of voting members of the governing body (Part VI, line 1a) . . . . .	<b>3</b> 10	
<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b) . . . . .	<b>4</b> 10	
<b>5</b> Total number of individuals employed in calendar year 2012 (Part V, line 2a) . . . . .	<b>5</b> 2	
<b>6</b> Total number of volunteers (estimate if necessary) . . . . .	<b>6</b> 40	
<b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12 . . . . .	<b>7a</b> 0	
<b>b</b> Net unrelated business taxable income from Form 990-T, line 34 . . . . .	<b>7b</b> 0	
<b>Revenue</b>	<b>8</b> Contributions and grants (Part VIII, line 1h) . . . . .	<b>Prior Year</b> 160,162 <b>Current Year</b> 112,315
	<b>9</b> Program service revenue (Part VIII, line 2g) . . . . .	22,709 23,304
	<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d) . . . . .	270 953
	<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) . . . . .	247,022 318,142
	<b>12</b> Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) . . . . .	430,163 454,714
<b>Expenses</b>	<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1–3) . . . . .	45,000 45,000
	<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4) . . . . .	0 0
	<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10) . . . . .	106,401 97,226
	<b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e) . . . . .	0 0
	<b>b</b> Total fundraising expenses (Part IX, column (D), line 25) ▶ <u>16,775</u>	
<b>17</b> Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e) . . . . .	116,210 132,162	
<b>18</b> Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25) . . . . .	267,611 274,388	
<b>19</b> Revenue less expenses. Subtract line 18 from line 12 . . . . .	162,552 180,326	
<b>Net Assets or Fund Balances</b>	<b>20</b> Total assets (Part X, line 16) . . . . .	<b>Beginning of Current Year</b> 623,761 <b>End of Year</b> 746,489
	<b>21</b> Total liabilities (Part X, line 26) . . . . .	66,535 8,937
	<b>22</b> Net assets or fund balances. Subtract line 21 from line 20 . . . . .	557,226 737,552

**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.

<b>Sign Here</b>	Signature of officer	Date
	<u>Annie Chapman</u> Type or print name and title	<u>treasurer</u>

<b>Paid Preparer Use Only</b>	Print/Type preparer's name	Preparer's signature	Date	Check <input checked="" type="checkbox"/> if self-employed	PTIN
	<u>Nan Mitchell</u>		<u>1/10/2014</u>		<u>P00142493</u>
	Firm's name ▶ <u>Nan S. Mitchell, CPA</u>	Firm's EIN ▶ <u>75-1647559</u>		Firm's address ▶ <u>10515 FM 349, Longview, TX 75603</u>	
			Phone no.	<u>(903) 643-9476</u>	

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 [ ]

1 Briefly describe the organization's mission: To provide support for persons affected by Syringomyelia and Chiari Malformation through support groups, information dissemination, conducting an annual medical conference, and distributing educational materials. Also to raise funds to provide grants for medical research.

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

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [ ] Yes [X] No If "Yes," describe these changes on Schedule O.

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

4a (Code: ) (Expenses \$ 165,042 including grants of \$ 0 ) (Revenue \$ ) ASAP works toward accomplishing its mission by providing Support and Education, Increasing awareness, early identification of patients and understanding of symptoms, cause and management of the disorders. We accomplish this through newsletters, website, annual medical conference, support group meetings, and webinars.

4b (Code: ) (Expenses \$ 45,000 including grants of \$ ) (Revenue \$ ) ASAP works toward accomplishing its mission by funding research. ASAP's goals include: increasing public awareness of the existence of the disorder and its devastating effects; financially supporting research efforts and raising funds to find all causes, to develop new treatments and to improve existing treatments coordinating the efforts of organizations working towards improving the lives of people with Syringomyelia and/or Chiari

4c (Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ )

4d Other program services. (Describe in Schedule O.) (Expenses \$ 0 including grants of \$ 0 ) (Revenue \$ 0 )

4e Total program service expenses 210,042

**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> (see instructions)?	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	<b>Section 501(c)(3) organizations.</b> Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II.</i>		X
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III.</i>		X
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I.</i>		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II.</i>		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III.</i>		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV.</i>		X
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V.</i>		X
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI.</i>	X	
b	Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII.</i>		X
c	Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII.</i>		X
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX.</i>		X
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X.</i>	X	
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X.</i>		X
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII.</i>	X	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional.</i>		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E.</i>		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?		X
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV.</i>		X
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or 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 (see instructions).</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?		X
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?		X
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		X
25a	<b>Section 501(c)(3) and 501(c)(4) organizations.</b> 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, highest 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, Part II, III, or IV, and Part V, line 1.</i>		X
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2.</i>		
36	<b>Section 501(c)(3) organizations.</b> 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 11b and 19? <b>Note.</b> All Form 990 filers are required to complete Schedule O.	X	

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Table with columns for question number, description, and Yes/No boxes. Includes questions 1a through 14b regarding Form 1096, Form W-2G, Form W-3, Form 990-T, Form 8886-T, Form 8282, Form 8899, Form 1098-C, Form 4966, Form 501(c)(7), Form 501(c)(12), Form 4947(a)(1), and Form 720.

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

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members included... 2 Did any officer, director, trustee, or key employee have a family relationship... 3 Did the organization delegate control over management duties... 4 Did the organization make any significant changes to its governing documents... 5 Did the organization become aware during the year of a significant diversion of the organization's assets... 6 Did the organization have members or stockholders... 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... 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body... 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: a The governing body? b Each committee with authority to act on behalf of the governing body? 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.

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates? 10b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11b Describe in Schedule O the process, if any, used by the organization to review this Form 990. 12a Did the organization have a written conflict of interest policy? If "No," go to line 13. 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done. 13 Did the organization have a written whistleblower policy? 14 Did the organization have a written document retention and destruction policy? 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? 15a The organization's CEO, Executive Director, or top management official. 15b Other officers or key employees of the organization. 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? 16b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed CA, FL, IL, MA, MD, MN, NJ, NY, OH, OR, PA, VA
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 [X] Another's website [X] Upon request [ ] Other (explain in Schedule O)
19 Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization: NAN MITCHELL, CPA (903) 643-9476
10515 FM 349, LONGVIEW, TX 75603

**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 (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)					(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee			
(1) Patrice Schaublin ----- President	20.00 ----- 0.00	X		X			0	0	0
(2) Karen McFarland ----- Secretary	2.00 ----- 0.00	X		X		X	0	0	0
(3) Bill Hagelgans ----- Treasurer	2.00 ----- 0.00	X		X			0	0	0
(4) John Heiss, MD ----- Medical Advisory Chair	1.00 ----- 0.00	X					0	0	0
(5) Barbara Banick ----- director	1.00 ----- 0.00	X				X	0	0	0
(6) Robert Keating, MD ----- Research chair	1.00 ----- 0.00	X					0	0	0
(7) Erol Veznedaroglu, MD ----- director	1.00 ----- 0.00	X		X			0	0	0
(8) Kerry Chu ----- Secretary	5.00 ----- 0.00	X		X			0	0	0
(9) John Caemmerer ----- director	5.00 ----- 0.00	X					0	0	0
(10) Annie Chapman ----- director	1.00 ----- 0.00	X					0	0	0
(11) Renee Tobias ----- director	1.00 ----- 0.00	X					0	0	0
(12) Lori Tutrow ----- director	3.00 ----- 0.00	X					0	0	0
(13) ----- -----	----- -----								
(14) ----- -----	----- -----								



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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(15) .....										
(16) .....										
(17) .....										
(18) .....										
(19) .....										
(20) .....										
(21) .....										
(22) .....										
(23) .....										
(24) .....										
(25) .....										
<b>1b Sub-total</b> .....							0	0	0	
<b>c Total from continuation sheets to Part VII, Section A</b> .....							0	0	0	
<b>d Total (add lines 1b and 1c)</b> .....							0	0	0	

**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 **0**

	Yes	No
<b>3</b> Did the organization list any <b>former</b> officer, director, or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual.</i> .....	X	
<b>4</b> 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
<b>5</b> 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
		0
		0
		0
		0
		0

**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**

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

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514	
Contributions, Gifts, Grants and Other Similar Amounts	<b>1a</b>	Federated campaigns . . . . .	<b>1a</b>	0				
	<b>b</b>	Membership dues . . . . .	<b>1b</b>	0				
	<b>c</b>	Fundraising events . . . . .	<b>1c</b>	0				
	<b>d</b>	Related organizations . . . . .	<b>1d</b>	0				
	<b>e</b>	Government grants (contributions) . . . . .	<b>1e</b>	0				
	<b>f</b>	All other contributions, gifts, grants, and similar amounts not included above . . . . .	<b>1f</b>	112,315				
	<b>g</b>	Noncash contributions included in lines 1a-1f: \$ . . . . .		0				
	<b>h</b>	<b>Total.</b> Add lines 1a-1f . . . . .		112,315				
	Program Service Revenue				<b>Business Code</b>			
<b>2a</b>		Medical Conference registration & other fees . . . . .		900099	23,304			
<b>b</b>		-----			0			
<b>c</b>		-----			0			
<b>d</b>		-----			0			
<b>e</b>		-----			0			
<b>f</b>		All other program service revenue . . . . .			0			
<b>g</b>		<b>Total.</b> Add lines 2a-2f . . . . .			23,304			
Other Revenue	<b>3</b>	Investment income (including dividends, interest, and other similar amounts) . . . . .			953			
	<b>4</b>	Income from investment of tax-exempt bond proceeds . . . . .			0			
	<b>5</b>	Royalties . . . . .			264,602			
	<b>6a</b>	Gross rents . . . . .	(i) Real		(ii) Personal			
			0		0			
	<b>b</b>	Less: rental expenses . . . . .						
	<b>c</b>	Rental income or (loss) . . . . .	0		0			
	<b>d</b>	Net rental income or (loss) . . . . .			0			
	<b>7a</b>	Gross amount from sales of assets other than inventory . . . . .	(i) Securities		(ii) Other			
			0		0			
	<b>b</b>	Less: cost or other basis and sales expenses . . . . .	0		0			
	<b>c</b>	Gain or (loss) . . . . .	0		0			
	<b>d</b>	Net gain or (loss) . . . . .			0			
	<b>8a</b>	Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18 . . . . .						
0			0					
51,869			1,519					
<b>b</b>	Less: direct expenses . . . . .	1,519		50,350				
<b>c</b>	Net income or (loss) from fundraising events . . . . .			50,350				
<b>9a</b>	Gross income from gaming activities. See Part IV, line 19 . . . . .							
		0		0				
<b>b</b>	Less: direct expenses . . . . .	0		0				
<b>c</b>	Net income or (loss) from gaming activities . . . . .			0				
<b>10a</b>	Gross sales of inventory, less returns and allowances . . . . .							
		3,190		0				
<b>b</b>	Less: cost of goods sold . . . . .	0		3,190				
<b>c</b>	Net income or (loss) from sales of inventory . . . . .			3,190				
Miscellaneous Revenue			<b>Business Code</b>					
<b>11a</b>	-----				0			
<b>b</b>	-----				0			
<b>c</b>	-----				0			
<b>d</b>	All other revenue . . . . .				0			
<b>e</b>	<b>Total.</b> Add lines 11a-11d . . . . .				0			
<b>12</b>	<b>Total revenue.</b> See instructions . . . . .				454,714	0	0	

**Part IX Statement of Functional Expenses**

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

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

<b>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</b>		(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	45,000	45,000		
2	Grants and other assistance to individuals in the United States. See Part IV, line 22	0			
3	Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16	0			
4	Benefits paid to or for members	0			
5	Compensation of current officers, directors, trustees, and key employees	0			
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0			
7	Other salaries and wages	89,702	69,031	16,944	3,727
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	0			
9	Other employee benefits	394	303	73	18
10	Payroll taxes	7,130	5,487	1,348	295
11	Fees for services (non-employees):				
a	Management	0			
b	Legal	0			
c	Accounting	20,178		20,178	
d	Lobbying	0			
e	Professional fundraising services. See Part IV, line 17	0			
f	Investment management fees	1,685		1,685	
g	Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.)	0			
12	Advertising and promotion	0			
13	Office expenses	1,872	1,665	207	
14	Information technology	8,713	7,406		1,307
15	Royalties	0			
16	Occupancy	3,600	2,700	900	
17	Travel	0			
18	Payments of travel or entertainment expenses for any federal, state, or local public officials	0			
19	Conferences, conventions, and meetings	50,209	50,209		
20	Interest	0			
21	Payments to affiliates	0			
22	Depreciation, depletion, and amortization	2,373	0	2,373	0
23	Insurance	4,471	2,189	2,168	114
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	Printing, Postage & shipping	17,553	16,886	36	631
b	State registration	1,421		1,135	286
c	Board & staff meetings	362		362	
d	Telephone & Internet	4,663	4,513	150	
e	All other expenses	15,062	4,653	12	10,397
25	<b>Total functional expenses.</b> Add lines 1 through 24e	274,388	210,042	47,571	16,775
26	<b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

**Part X Balance Sheet**

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

		(A)		(B)
		Beginning of year		End of year
<b>Assets</b>	<b>1</b> Cash—non-interest-bearing . . . . .	118,289	<b>1</b>	119,660
	<b>2</b> Savings and temporary cash investments . . . . .	273,155	<b>2</b>	560,981
	<b>3</b> Pledges and grants receivable, net . . . . .	0	<b>3</b>	0
	<b>4</b> Accounts receivable, net . . . . .	202,538	<b>4</b>	17,399
	<b>5</b> Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L . . . . .		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions). Complete Part II of Schedule L . . . . .		<b>6</b>	
	<b>7</b> Notes and loans receivable, net . . . . .	0	<b>7</b>	0
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges . . . . .	9,338	<b>9</b>	9,963
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	<b>10a</b> 33,438		
	<b>b</b> Less: accumulated depreciation . . . . .	<b>10b</b> 12,375	3,018	<b>10c</b> 21,063
	<b>11</b> Investments—publicly traded securities . . . . .	0	<b>11</b>	0
	<b>12</b> Investments—other securities. See Part IV, line 11 . . . . .	0	<b>12</b>	0
	<b>13</b> Investments—program-related. See Part IV, line 11 . . . . .	0	<b>13</b>	0
	<b>14</b> Intangible assets . . . . .		<b>14</b>	0
	<b>15</b> Other assets. See Part IV, line 11 . . . . .	17,423	<b>15</b>	17,423
<b>16</b> <b>Total assets.</b> Add lines 1 through 15 (must equal line 34) . . . . .	623,761	<b>16</b>	746,489	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	15,962	<b>17</b>	6,925
	<b>18</b> Grants payable . . . . .	45,000	<b>18</b>	
	<b>19</b> Deferred revenue . . . . .	4,067	<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities . . . . .		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D . . . . .		<b>21</b>	
	<b>22</b> Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L . . . . .		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .	0	<b>23</b>	0
	<b>24</b> Unsecured notes and loans payable to unrelated third parties . . . . .	0	<b>24</b>	0
	<b>25</b> 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 . . . . .	1,506	<b>25</b>	2,012
	<b>26</b> <b>Total liabilities.</b> Add lines 17 through 25 . . . . .	66,535	<b>26</b>	8,937
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow SFAS 117 (ASC 958), check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27 through 29, and lines 33 and 34.</b>			
	<b>27</b> Unrestricted net assets . . . . .	348,754	<b>27</b>	559,104
	<b>28</b> Temporarily restricted net assets . . . . .	208,472	<b>28</b>	178,448
	<b>29</b> Permanently restricted net assets . . . . .		<b>29</b>	
	<b>Organizations that do not follow SFAS 117 (ASC958), check here</b> <input type="checkbox"/> <b>and complete lines 30 through 34.</b>			
	<b>30</b> Capital stock or trust principal, or current funds . . . . .		<b>30</b>	
	<b>31</b> Paid-in or capital surplus, or land, building, or equipment fund . . . . .		<b>31</b>	
	<b>32</b> Retained earnings, endowment, accumulated income, or other funds . . . . .		<b>32</b>	
<b>33</b> Total net assets or fund balances . . . . .	557,226	<b>33</b>	737,552	
<b>34</b> Total liabilities and net assets/fund balances . . . . .	623,761	<b>34</b>	746,489	

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12) . . . . .	<b>1</b>	454,714
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25) . . . . .	<b>2</b>	274,388
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1 . . . . .	<b>3</b>	180,326
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A)) . . . . .	<b>4</b>	557,226
<b>5</b>	Net unrealized gains (losses) on investments . . . . .	<b>5</b>	
<b>6</b>	Donated services and use of facilities . . . . .	<b>6</b>	
<b>7</b>	Investment expenses . . . . .	<b>7</b>	
<b>8</b>	Prior period adjustments . . . . .	<b>8</b>	
<b>9</b>	Other changes in net assets or fund balances (explain in Schedule O) . . . . .	<b>9</b>	
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B)) . . . . .	<b>10</b>	737,552

**Part XII Financial Statements and Reporting**

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

		Yes	No
<b>1</b>	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.		
<b>2a</b>	Were the organization's financial statements compiled or reviewed by an independent accountant? . . . . . If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
<b>b</b>	Were the organization's financial statements audited by an independent accountant? . . . . . If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	X	
<b>c</b>	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	
<b>3a</b>	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
<b>b</b>	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits . . . . .		

Depreciation and Amortization (Including Information on Listed Property)

Department of the Treasury Internal Revenue Service (99)

See separate instructions. Attach to your tax return.

Attachment Sequence No. 179

Name(s) shown on return Business or activity to which this form relates Identifying number AMERICAN SYRINGOMYELIA ALLIANCE PRO 990 75-2245195

Part I Election To Expense Certain Property Under Section 179

Note: If you have any listed property, complete Part V before you complete Part I.

Table with 5 main rows for Section 179 election. Line 1: Maximum amount. Line 2: Total cost. Line 3: Threshold cost. Line 4: Reduction in limitation. Line 5: Dollar limitation. Line 6-13: Detailed property information and carryover calculations.

Note: Do not use Part II or Part III below for listed property. Instead, use Part V.

Part II Special Depreciation Allowance and Other Depreciation (Do not include listed property.) (See instructions.)

Table with 3 rows for Part II. Line 14: Special depreciation allowance. Line 15: Property subject to section 168(f)(1) election. Line 16: Other depreciation (including ACRS).

Part III MACRS Depreciation (Do not include listed property.) (See instructions.)

Section A

Table with 2 rows for Section A. Line 17: MACRS deductions for assets placed in service in tax years beginning before 2012. Line 18: If you are electing to group any assets placed in service during the tax year into one or more general asset accounts, check here.

Section B - Assets Placed in Service During 2012 Tax Year Using the General Depreciation System

Table with 7 columns: (a) Classification of property, (b) Month and year placed in service, (c) Basis for depreciation, (d) Recovery period, (e) Convention, (f) Method, (g) Depreciation deduction. Rows 19a-i list various property types and their depreciation details.

Section C - Assets Placed in Service During 2012 Tax Year Using the Alternative Depreciation System

Table with 6 columns: (a) Class life, (b) Month and year placed in service, (c) Basis for depreciation, (d) Recovery period, (e) Convention, (f) Method, (g) Depreciation deduction. Rows 20a-c list class life options.

Part IV Summary (See instructions.)

Table with 2 rows for Part IV. Line 21: Listed property. Line 22: Total. Line 23: For assets shown above and placed in service during the current year, enter the portion of the basis attributable to section 263A costs.

For Paperwork Reduction Act Notice, see separate instructions.

**Part V**

**Listed Property** (Include automobiles, certain other vehicles, certain computers, and property used for entertainment, recreation, or amusement.)

**Note:** For any vehicle for which you are using the standard mileage rate or deducting lease expense, complete only 24a, 24b, columns (a) through (c) of Section A, all of Section B, and Section C if applicable.

**Section A—Depreciation and Other Information (Caution: See the instructions for limits for passenger automobiles.)**

<b>24a</b> Do you have evidence to support the business/investment use claimed? <input type="checkbox"/> Yes <input type="checkbox"/> No					<b>24b</b> If "Yes," is the evidence written? <input type="checkbox"/> Yes <input type="checkbox"/> No				
(a) Type of property (list vehicles first)	(b) Date placed in service	(c) Business/ investment use percentage	(d) Cost or other basis	(e) Basis for depreciation (business/ investment use only)	(f) Recovery period	(g) Method/ Convention	(h) Depreciation deduction	(i) Elected section 179 cost	
<b>25</b> Special depreciation allowance for qualified listed property placed in service during the tax year and used more than 50% in a qualified business use (see instructions) . . . . .							<b>25</b>		
<b>26</b> Property used more than 50% in a qualified business use:									
		%							
		%							
		%							
<b>27</b> Property used 50% or less in a qualified business use:									
		%				S/L -			
		%				S/L -			
		%				S/L -			
<b>28</b> Add amounts in column (h), lines 25 through 27. Enter here and on line 21, page 1 . . . . .							<b>28</b>	0	
<b>29</b> Add amounts in column (i), line 26. Enter here and on line 7, page 1 . . . . .								<b>29</b>	0

**Section B—Information on Use of Vehicles**

Complete this section for vehicles used by a sole proprietor, partner, or other "more than 5% owner," or related person. If you provided vehicles to your employees, first answer the questions in Section C to see if you meet an exception to completing this section for those vehicles.

30 Total business/investment miles driven during the year (do not include commuting miles) . . . . .	(a) Vehicle 1		(b) Vehicle 2		(c) Vehicle 3		(d) Vehicle 4		(e) Vehicle 5		(f) Vehicle 6	
31 Total commuting miles driven during the year . . . . .												
32 Total other personal (noncommuting) miles driven . . . . .												
33 Total miles driven during the year. Add lines 30 through 32 . . . . .												
34 Was the vehicle available for personal use during off-duty hours? . . . . .	Yes No		Yes No		Yes No		Yes No		Yes No		Yes No	
35 Was the vehicle used primarily by a more than 5% owner or related person? . . . . .												
36 Is another vehicle available for personal use? . . . . .												

**Section C—Questions for Employers Who Provide Vehicles for Use by Their Employees**

Answer these questions to determine if you meet an exception to completing Section B for vehicles used by employees who are not more than 5% owners or related persons (see instructions).

37 Do you maintain a written policy statement that prohibits all personal use of vehicles, including commuting, by your employees? . . . . .		Yes	No
38 Do you maintain a written policy statement that prohibits personal use of vehicles, except commuting, by your employees? See the instructions for vehicles used by corporate officers, directors, or 1% or more owners . . . . .			
39 Do you treat all use of vehicles by employees as personal use? . . . . .			
40 Do you provide more than five vehicles to your employees, obtain information from your employees about the use of the vehicles, and retain the information received? . . . . .			
41 Do you meet the requirements concerning qualified automobile demonstration use? (See instructions.) . . . . .			
<b>Note:</b> If your answer to 37, 38, 39, 40, or 41 is "Yes," do not complete Section B for the covered vehicles.			

**Part VI**

**Amortization**

(a) Description of costs	(b) Date amortization begins	(c) Amortizable amount	(d) Code section	(e) Amortization period or percentage	(f) Amortization for this year	
<b>42</b> Amortization of costs that begins during your 2012 tax year (see instructions):						
<b>43</b> Amortization of costs that began before your 2012 tax year . . . . .					<b>43</b>	2,062
<b>44 Total.</b> Add amounts in column (f). See the instructions for where to report . . . . .					<b>44</b>	2,062

**SCHEDULE A**  
**(Form 990 or 990-EZ)**

**Public Charity Status and Public Support**

OMB No. 1545-0047

**2012**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

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.

Name of the organization

AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.

Employer identification number

75-2245195

**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—Non-functionally integrated
  - 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?
    - (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?
    - (ii) A family member of a person described in (i) above?
    - (iii) A 35% controlled entity of a person described in (i) or (ii) above?

	Yes	No
11g(i)		
11g(ii)		
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 monetary support
			Yes	No	Yes	No	Yes	No	
(A)									
(B)									
(C)									
(D)									
(E)									
<b>Total</b>									0



**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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") . . . . .	194,018	244,787	200,655	160,162	112,315	911,937
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						0
3 The value of services or facilities furnished by a governmental unit to the organization without charge . . . . .						0
4 <b>Total.</b> Add lines 1 through 3 . . . . .	194,018	244,787	200,655	160,162	112,315	911,937
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 <b>Public support.</b> Subtract line 5 from line 4.						911,937

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7 Amounts from line 4 . . . . .	194,018	244,787	200,655	160,162	112,315	911,937
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . . . .	47,083	96,095	691	164,307	265,555	573,731
9 Net income from unrelated business activities, whether or not the business is regularly carried on . . . . .	0					0
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.) . . . . .	47,649	33,483	95,604	105,694	76,844	359,274
11 <b>Total support.</b> Add lines 7 through 10 . . . . .						1,844,942
12 Gross receipts from related activities, etc. (see instructions) . . . . .					12	
13 <b>First five years.</b> 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 <b>stop here</b> . . . . . ▶ <input type="checkbox"/>						

**Section C. Computation of Public Support Percentage**

14 Public support percentage for 2012 (line 6, column (f) divided by line 11, column (f)) . . . . .	14	49.43%
15 Public support percentage from 2011 Schedule A, Part II, line 14 . . . . .	15	64.36%
16a <b>33 1/3% support test—2012.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . . ▶ <input checked="" type="checkbox"/>		
b <b>33 1/3% support test—2011.</b> 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 <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . . ▶ <input type="checkbox"/>		
17a <b>10%-facts-and-circumstances test—2012.</b> 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 <b>stop here.</b> 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 <b>10%-facts-and-circumstances test—2011.</b> 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 <b>stop here.</b> 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 <b>Private foundation.</b> 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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						0
<b>2</b> 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 . . . . .						0
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 . . . . .						0
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						0
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge . . . . .						0
<b>6 Total.</b> Add lines 1 through 5 . . . . .	0	0	0	0	0	0
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons . . . . .	0					0
<b>b</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					0
<b>c</b> Add lines 7a and 7b . . . . .	0	0	0	0	0	0
<b>8 Public support</b> (Subtract line 7c from line 6.) . . . . .						0

**Section B. Total Support**

Calendar year (or fiscal year beginning in)	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
<b>9</b> Amounts from line 6 . . . . .	0	0	0	0	0	0
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						0
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 . . . . .						0
<b>c</b> Add lines 10a and 10b . . . . .	0	0	0	0	0	0
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on . . . . .	0					0
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.) . . . . .						0
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.) . . . . .	0	0	0	0	0	0

**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**

<b>15</b> Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f)) . . . . .	<b>15</b>	0.00%
<b>16</b> Public support percentage from 2011 Schedule A, Part III, line 15 . . . . .	<b>16</b>	0.00%

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for <b>2012</b> (line 10c, column (f) divided by line 13, column (f)) . . . . .	<b>17</b>	0.00%
<b>18</b> Investment income percentage from <b>2011</b> Schedule A, Part III, line 17 . . . . .	<b>18</b>	0.00%

**19a 33 1/3% support tests—2012.** 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—2011.** 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 . . . . .

**Part IV**

**Supplemental Information.** Complete this part to provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Also complete this part for any additional information. (See instructions).

Ruled area for supplemental information with horizontal dashed lines.

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

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

▶ **Attach to Form 990, Form 990-EZ, or Form 990-PF.**

OMB No. 1545-0047

**2012**

**Name of the organization**

**Employer identification number**

AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.

75-2245195

**Organization type** (check one):

**Filers of:**

**Section:**

Form 990 or 990-EZ

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

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

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

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

501(c)(3) taxable private foundation

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

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

**General Rule**

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

**Special Rules**

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

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

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

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

<b>Name of organization</b> AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.	<b>Employer identification number</b> 75-2245195
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**Part I Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	Monkton Institute ----- 15156 Manor Rd ----- Monkton MD 21111 Foreign State or Province: _____ Foreign Country: _____	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
2	Beverly VanHovel Trust ----- 216 South 4th St. ----- Wataska IL 60970 Foreign State or Province: _____ Foreign Country: _____	\$ 43,643	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
-----	----- ----- ----- Foreign State or Province: _____ Foreign Country: _____	\$ -----	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
-----	----- ----- ----- Foreign State or Province: _____ Foreign Country: _____	\$ -----	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
-----	----- ----- ----- Foreign State or Province: _____ Foreign Country: _____	\$ -----	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
-----	----- ----- ----- Foreign State or Province: _____ Foreign Country: _____	\$ -----	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
-----	----- ----- ----- Foreign State or Province: _____ Foreign Country: _____	\$ -----	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)

<b>Name of organization</b> AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.	<b>Employer identification number</b> 75-2245195
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**Part II** **Noncash Property** (see instructions). Use duplicate copies of Part II if additional space is needed.

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

<b>Name of organization</b> AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.	<b>Employer identification number</b> 75-2245195
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**Part III** **Exclusively religious, charitable, etc., individual contributions to section 501(c)(7), (8), or (10) organizations total more than \$1,000 for the year.** Complete columns (a) through (e) and the following line entry.  
 For organizations completing Part III, enter the total of *exclusively* religious, charitable, etc., contributions of **\$1,000 or less** for the year. (Enter this information once. See instructions.) ▶ \$ ..... 0  
 Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
-----	----- ----- -----	----- ----- -----	----- ----- -----

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
----- ----- ----- For. Prov.                      Country	----- ----- -----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
-----	----- ----- -----	----- ----- -----	----- ----- -----

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
----- ----- ----- For. Prov.                      Country	----- ----- -----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
-----	----- ----- -----	----- ----- -----	----- ----- -----

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
----- ----- ----- For. Prov.                      Country	----- ----- -----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
-----	----- ----- -----	----- ----- -----	----- ----- -----

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
----- ----- ----- For. Prov.                      Country	----- ----- -----

**SCHEDULE C**  
**(Form 990 or 990-EZ)**

**Political Campaign and Lobbying Activities**

OMB No. 1545-0047

**2012**

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

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

▶ **See separate instructions.**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

**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 <b>AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.</b>	Employer identification number <b>75-2245195</b>
--	---

**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 . . . . . ▶ \$ \_\_\_\_\_ 0
- 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-.
(1)	_____	_____	_____	_____
(2)	_____	_____	_____	_____
(3)	_____	_____	_____	_____
(4)	_____	_____	_____	_____
(5)	_____	_____	_____	_____
(6)	_____	_____	_____	_____



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

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

<b>Limits on Lobbying Expenditures</b> (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
<b>1a</b>	Total lobbying expenditures to influence public opinion (grass roots lobbying) . . . . .	0	0												
<b>b</b>	Total lobbying expenditures to influence a legislative body (direct lobbying) . . . . .	0	0												
<b>c</b>	Total lobbying expenditures (add lines 1a and 1b) . . . . .	0	0												
<b>d</b>	Other exempt purpose expenditures . . . . .	0	0												
<b>e</b>	Total exempt purpose expenditures (add lines 1c and 1d) . . . . .	0	0												
<b>f</b>	Lobbying nontaxable amount. Enter the amount from the following table in both columns.	0	0												
<table border="1" style="width: 100%;"> <thead> <tr> <th style="width: 50%;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width: 50%;">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.														
<b>g</b>	Grassroots nontaxable amount (enter 25% of line 1f) . . . . .	0	0												
<b>h</b>	Subtract line 1g from line 1a. If zero or less, enter -0- . . . . .	0	0												
<b>i</b>	Subtract line 1f from line 1c. If zero or less, enter -0- . . . . .	0	0												
<b>j</b>	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.)

<b>Lobbying Expenditures During 4-Year Averaging Period</b>					
Calendar year (or fiscal year beginning in)	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) Total
<b>2a</b> Lobbying nontaxable amount				0	0
<b>b</b> Lobbying ceiling amount (150% of line 2a, column(e))					0
<b>c</b> Total lobbying expenditures				0	0
<b>d</b> Grassroots nontaxable amount				0	0
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					0
<b>f</b> Grassroots lobbying expenditures				0	0

**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
<b>1</b> 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:			
<b>a</b> Volunteers? . . . . .			
<b>b</b> Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?			
<b>c</b> Media advertisements? . . . . .			
<b>d</b> Mailings to members, legislators, or the public? . . . . .			
<b>e</b> Publications, or published or broadcast statements? . . . . .			
<b>f</b> Grants to other organizations for lobbying purposes? . . . . .			
<b>g</b> Direct contact with legislators, their staffs, government officials, or a legislative body? . . . . .			
<b>h</b> Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means? . . . . .			
<b>i</b> Other activities? . . . . .			
<b>j</b> Total. Add lines 1c through 1i . . . . .			0
<b>2a</b> Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?			
<b>b</b> If "Yes," enter the amount of any tax incurred under section 4912 . . . . .			
<b>c</b> If "Yes," enter the amount of any tax incurred by organization managers under section 4912 . . . . .			
<b>d</b> 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
<b>1</b> Were substantially all (90% or more) dues received nondeductible by members? . . . . .	1	
<b>2</b> Did the organization make only in-house lobbying expenditures of \$2,000 or less? . . . . .	2	
<b>3</b> 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."**

<b>1</b> Dues, assessments and similar amounts from members . . . . .	<b>1</b>	
<b>2</b> Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).		
<b>a</b> Current year . . . . .	<b>2a</b>	
<b>b</b> Carryover from last year . . . . .	<b>2b</b>	
<b>c</b> Total . . . . .	<b>2c</b>	0
<b>3</b> Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues . . . . .	<b>3</b>	
<b>4</b> 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? . . . . .	<b>4</b>	
<b>5</b> Taxable amount of lobbying and political expenditures (see instructions) . . . . .	<b>5</b>	0

**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 (affiliated group list); Part II-A, line 2; and Part II-B, line 1. Also, complete this part for any additional information.

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**Part IV** Supplemental Information *(continued)*

Area with horizontal dashed lines for supplemental information.

**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

**2012**

**Open to Public Inspection**

Name of the organization AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.	Employer identification number 75-2245195
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**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.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year . . . . .		
2 Aggregate contributions to (during year)		
3 Aggregate grants from (during year) . . . . .		
4 Aggregate value at end of year . . . . .		
5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? . . . . . <input type="checkbox"/> Yes <input type="checkbox"/> No		
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? . . . . . <input type="checkbox"/> Yes <input type="checkbox"/> No		

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

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

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or education)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> Preservation of open space	

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

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

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

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

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

6 Staff and volunteer hours devoted to monitoring, inspecting, and enforcing conservation easements during the year ▶ \_\_\_\_\_

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

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

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

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

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

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

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

(i) Revenues included in Form 990, Part VIII, line 1 . . . . . ▶ \$ \_\_\_\_\_

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

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

a Revenues included in Form 990, Part VIII, line 1 . . . . . ▶ \$ \_\_\_\_\_

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

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

- 3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
- a  Public exhibition
  - b  Scholarly research
  - c  Preservation for future generations
  - d  Loan or exchange programs
  - e  Other .....
- 4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? . . . . .  Yes  No

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

- 1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? . . . . .  Yes  No
- b If "Yes," explain the arrangement in Part XIII and complete the following table:
- |   | Amount |
|---|--------|
| c Beginning balance . . . . .             | 0      |
| d Additions during the year . . . . .     |        |
| e Distributions during the year . . . . . |        |
| f Ending balance . . . . .                | 0      |
- 2a Did the organization include an amount on Form 990, Part X, line 21? . . . . .  Yes  No
- b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII . . . . .

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance . . . . .	0	0			
b Contributions . . . . .					
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 . . . . .	0	0	0	0	0

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment ▶ \_\_\_\_\_ %
  - b Permanent endowment ▶ \_\_\_\_\_ %
  - c Temporarily restricted endowment ▶ \_\_\_\_\_ %
- The percentages 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 . . . . . | <input type="checkbox"/> | <input type="checkbox"/> |
| (ii) related organizations . . . . .  | <input type="checkbox"/> | <input type="checkbox"/> |
- b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R? . . . . .
- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

**Part VI Land, Buildings, and Equipment.** 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 . . . . .	0	0		0
b Buildings . . . . .	0	0	0	0
c Leasehold improvements . . . . .	0	0	0	0
d Equipment . . . . .	0	5,595	4,950	645
e Other . . . . .	0	27,843	7,425	20,418

**Total.** Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).) . . . . . ▶ 21,063

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

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives . . . . .	0	
(2) Closely-held equity interests . . . . .	0	
(3) Other -----		
(A) -----		
(B) -----		
(C) -----		
(D) -----		
(E) -----		
(F) -----		
(G) -----		
(H) -----		
(I) -----		
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 12.) ▶	0	

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

(a) Description of investment type	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 13.) ▶	0	

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

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 15.) . . . . . ▶	0

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	0
(2) Accrued wages and payroll liabilities	2,012
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	2,012

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

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

<b>1</b>	Total revenue, gains, and other support per audited financial statements . . . . .		<b>1</b>	456,233
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
<b>a</b>	Net unrealized gains on investments . . . . .	<b>2a</b>		
<b>b</b>	Donated services and use of facilities . . . . .	<b>2b</b>		
<b>c</b>	Recoveries of prior year grants . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>	1,519	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	1,519
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	454,714
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	0
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.) . . . . .		<b>5</b>	454,714

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

<b>1</b>	Total expenses and losses per audited financial statements . . . . .		<b>1</b>	275,907
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
<b>a</b>	Donated services and use of facilities . . . . .	<b>2a</b>		
<b>b</b>	Prior year adjustments . . . . .	<b>2b</b>		
<b>c</b>	Other losses . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>	1,519	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	1,519
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	274,388
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	0
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.) . . . . .		<b>5</b>	274,388

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

Part XI Line 2 d Fundraising event expenses \_\_\_\_\_

Part XII Line 2 d Fund raising event expenses \_\_\_\_\_

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**Part XIII** Supplemental Information *(continued)*

Area with horizontal dashed lines for supplemental information.



**SCHEDULE G**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

Name of the organization

**Supplemental Information Regarding  
Fundraising or Gaming Activities**

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.

OMB No. 1545-0047

**2012**

**Open to Public  
Inspection**

AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.

Employer identification number

75-2245195

**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
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  Yes  No
- b** If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

	(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
			Yes	No			
1					0	0	0
2					0	0	0
3					0	0	0
4					0	0	0
5					0	0	0
6					0	0	0
7					0	0	0
8					0	0	0
9					0	0	0
10					0	0	0
<b>Total</b>					0	0	0

- 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.

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**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	
		Various Walks (event type)	Member sponsored Eve (event type)	NONE (total number)	(add col. (a) through col. (c))	
Revenue	1	Gross receipts . . . . .	23,411	28,458	0	51,869
	2	Less: Contributions . . . . .			0	0
	3	Gross income (line 1 minus line 2) . . . . .	23,411	28,458	0	51,869
Direct Expenses	4	Cash prizes . . . . .			0	0
	5	Noncash prizes . . . . .			0	0
	6	Rent/facility costs . . . . .			0	0
	7	Food and beverages . . . . .			0	0
	8	Entertainment . . . . .			0	0
	9	Other direct expenses . . . . .	324	1,195	0	1,519
	10	Direct expense summary. Add lines 4 through 9 in column (d) . . . . .				( 1,519)
11	Net income summary. Combine line 3, column (d), and line 10 . . . . .				50,350	

**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 . . . . .			0
	3	Noncash prizes . . . . .			0
	4	Rent/facility costs . . . . .			0
	5	Other direct expenses . . . . .			0
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) . . . . .				( 0)
8	Net gaming income summary. Combine line 1, column d, and line 7 . . . . .				0

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 ▶ \$ \_\_\_\_\_ 0 and the amount of gaming revenue retained by the third party ▶ \$ \_\_\_\_\_ 0 .

c If "Yes," enter name and address of the third party:

Name ▶ \_\_\_\_\_

Address ▶ \_\_\_\_\_

16 Gaming manager information:

Name ▶ \_\_\_\_\_

Gaming manager compensation ▶ \$ \_\_\_\_\_ 0

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 ▶ \$ \_\_\_\_\_ 0

**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).

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**SCHEDULE I  
(Form 990)**

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

OMB No. 1545-0047

**2012**

**Open to Public  
Inspection**

Department of the Treasury  
Internal Revenue Service

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

▶ Attach to Form 990.

Name of the organization

AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.

Employer identification number

75-2245195

**Part I General Information on Grants and Assistance**

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

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

<b>1 (a)</b> Name and address of organization or government	<b>(b)</b> EIN	<b>(c)</b> IRC section if applicable	<b>(d)</b> Amount of cash grant	<b>(e)</b> Amount of non-cash assistance	<b>(f)</b> Method of valuation (book, FMV, appraisal, other)	<b>(g)</b> Description of non-cash assistance	<b>(h)</b> Purpose of grant or assistance
(1) Univ. of Wisconsin - Madison 600 Highland Ave Madison, WI 53792			45,000				Medical Research
(2) -----							
(3) -----							
(4) -----							
(5) -----							
(6) -----							
(7) -----							
(8) -----							
(9) -----							
(10) -----							
(11) -----							
(12) -----							

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

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

Schedule I (Form 990) (2012)

**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
1					
2					
3					
4					
5					
6					
7					

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

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**SCHEDULE J  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

Name of the organization

AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.

**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

**2012**

**Open to Public Inspection**

Employer identification number

75-2245195

**Part I Questions Regarding Compensation**

**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.

- |  |  |
|--|--|
| <input type="checkbox"/> First-class or charter travel             | <input type="checkbox"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions                     | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax indemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees   |
| <input type="checkbox"/> Discretionary spending account            | <input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef) |

**b** If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain . . . . .

**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? . . . . .

**3** Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.

- |  |  |
|--|--|
| <input type="checkbox"/> Compensation committee              | <input type="checkbox"/> Written employment contract                     |
| <input type="checkbox"/> Independent compensation consultant | <input type="checkbox"/> Compensation survey or study                    |
| <input type="checkbox"/> Form 990 of other organizations     | <input type="checkbox"/> Approval by the board or compensation committee |

**4** During the year, did any person listed in Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:

- a** Receive a severance payment or change-of-control payment? . . . . .
- b** Participate in, or receive payment from, a supplemental nonqualified retirement plan? . . . . .
- c** Participate in, or receive payment from, an equity-based compensation arrangement? . . . . .
- If "Yes" to any of lines 4a–c, list the persons and provide the applicable amounts for each item in Part III.

**Only section 501(c)(3) and 501(c)(4) organizations must complete lines 5–9.**

**5** For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:

- a** The organization? . . . . .
- b** Any related organization? . . . . .
- If "Yes" to line 5a or 5b, describe in Part III.

**6** For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:

- a** The organization? . . . . .
- b** Any related organization? . . . . .
- If "Yes" to line 6a or 6b, describe in Part III.

**7** For persons listed in Form 990, Part VII, Section A, line 1a, did the organization provide any non-fixed payments not described in lines 5 and 6? If "Yes," describe in Part III . . . . .

**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 . . . . .

**9** If "Yes" to line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)? . . . . .

	Yes	No
<b>1b</b>		
<b>2</b>		
<b>4a</b>		X
<b>4b</b>		X
<b>4c</b>		X
<b>5a</b>		X
<b>5b</b>		X
<b>6a</b>		X
<b>6b</b>		X
<b>7</b>		X
<b>8</b>		X
<b>9</b>		

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

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

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

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)–(D)	(F) Compensation reported as deferred in prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
1	Karen McFarland Secretary	(i)					0	
	(ii)						0	
2	Barbara Banick director	(i)					0	
	(ii)						0	
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)							

**Part III Supplemental Information**

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

Lined area for supplemental information with horizontal dashed lines.



**SCHEDULE O**  
**(Form 990 or 990-EZ)**

**Supplemental Information to Form 990 or 990-EZ**

OMB No. 1545-0047

**2012**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

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.

Name of the organization

AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.

Employer identification number

75-2245195

Form 990 Part IX Line 24 e Miscellaneous Expense \$ 162, Merchandise & Resource Materials

\$1,892, Equipment Lease & Maintenance \$3,600, Dues & Subscriptions \$1,050, General Development

Expense \$8,358

Form 990 Part VI Section B Line 11 b Treasurer reviews the 990 before signing and filing,

circulated to board members afterward

Form 990 Part VI Section C Line 19 Notification is made via the organization's web site and

Guidestar

Name of the organization

Employer identification number

AMERICAN SYRINGOMYELIA ALLIANCE PROJECT, INC.

75-2245195

Dotted lines for supplemental information.

**Part I (8868 Page 1) - Members Included in Extension**

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	Name	Street Address	City	State	ZIP code	Foreign Country	EIN
1							