

Form **990**

**Return of Organization Exempt From Income Tax**

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

OMB No. 1545-0047

**2020**

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

Do not enter social security numbers on this form as it may be made public.

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

**A** For the **2020** calendar year, or tax year beginning and ending

**B** Check if applicable:

- Address change
- Name change
- Initial return
- Final return/terminated
- Amended return
- Application pending

**C** Name of organization: **SPINA BIFIDA ASSOCIATION OF AMERICA**  
 Doing business as: \_\_\_\_\_  
 Number and street (or P.O. box if mail is not delivered to street address) Room/suite: **1600 WILSON BOULEVARD 800**  
 City or town, state or province, country, and ZIP or foreign postal code: **ARLINGTON, VA 22209**

**D** Employer identification number: **58-1342181**

**E** Telephone number: **(202) 944-3285**

**G** Gross receipts \$: **1,856,663.**

**H(a)** Is this a group return for subordinates?  Yes  No  
**H(b)** Are all subordinates included?  Yes  No  
 If "No," attach a list. See instructions

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

**J** Website: **WWW.SBAA.ORG**

**K** Form of organization:  Corporation  Trust  Association  Other

**L** Year of formation: **1973** **M** State of legal domicile: **WI**

**H(c)** Group exemption number

**Part I Summary**

<b>Activities &amp; Governance</b>	<b>1</b> Briefly describe the organization's mission or most significant activities: <b>TO PROMOTE THE PREVENTION OF SPINA BIFIDA AND ENHANCE THE LIVES OF ALL AFFECTED. THE MISSION OF</b>		
	<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>	<b>13</b>
	<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)	<b>4</b>	<b>13</b>
	<b>5</b> Total number of individuals employed in calendar year 2020 (Part V, line 2a)	<b>5</b>	<b>14</b>
	<b>6</b> Total number of volunteers (estimate if necessary)	<b>6</b>	<b>550</b>
	<b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12	<b>7a</b>	<b>0.</b>
<b>b</b> Net unrelated business taxable income from Form 990-T, Part I, line 11	<b>7b</b>	<b>0.</b>	
<b>Revenue</b>	<b>8</b> Contributions and grants (Part VIII, line 1h)	<b>Prior Year</b> 1,718,305.	<b>Current Year</b> 1,460,028.
	<b>9</b> Program service revenue (Part VIII, line 2g)	111,811.	37,489.
	<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)	24,772.	23,004.
	<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	-883.	928.
	<b>12</b> Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,854,005.	1,521,449.
	<b>Expenses</b>	<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)	35,220.
<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)		1,253,138.	1,294,837.
<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) <b>271,446.</b>			
<b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		943,706.	743,810.
<b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	2,232,064.	2,051,396.	
<b>19</b> Revenue less expenses. Subtract line 18 from line 12	-378,059.	-529,947.	
<b>Net Assets or Fund Balances</b>	<b>20</b> Total assets (Part X, line 16)	<b>Beginning of Current Year</b> 1,680,010.	<b>End of Year</b> 1,403,641.
	<b>21</b> Total liabilities (Part X, line 26)	270,770.	493,546.
	<b>22</b> Net assets or fund balances. Subtract line 21 from line 20	1,409,240.	910,095.

**Part II Signature Block**

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

**Sign Here**

Signature of officer: *[Signature]* Date: **9/13/2021**

**SARA STRUWE, PRESIDENT AND CEO**  
Type or print name and title

**Paid** Print/Type preparer's name: **AARON M. FOX** Preparer's signature: *[Signature]* Date: **09/13/21** Check if self-employed:  PTIN: **P01365820**

**Preparer Use Only** Firm's name: **MARCUM LLP** Firm's EIN: **11-1986323**  
Firm's address: **1899 L STREET, NW, SUITE 850 WASHINGTON, DC 20036** Phone no.: **(202) 227-4000**

May the IRS discuss this return with the preparer shown above? See instructions  Yes  No

**SEE SCHEDULE O FOR ORGANIZATION MISSION STATEMENT CONTINUATION COPY**

\*\*\* ELECTRONICALLY FILED ON 09/13/2021 \*\*\*

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: TO PROVIDE INFORMATION ABOUT THE BIRTH DEFECT OF SPINA BIFIDA AND ITS RELATED CONDITIONS AND SUPPORT TO INDIVIDUALS LIVING WITH IT THROUGH EDUCATION, ADVOCACY, RESEARCH, AND SERVICE; TO FACILITATE RESEARCH INTO THE CAUSES, EFFECTS, AND TREATMENT OF SPINA BIFIDA; AND TO

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [ ] Yes [X] No 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 \$ 698,632. including grants of \$ 2,250. ) (Revenue \$ ) RESEARCH AND CLINICAL CARE - THE SPINA BIFIDA ASSOCIATION (THE ASSOCIATION) DEVELOPED THE SPINA BIFIDA COLLABORATIVE CARE NETWORK (SBCCN) TO IMPROVE THE HEALTH CARE OF PEOPLE WITH SPINA BIFIDA, ENABLING THEM TO HAVE BETTER CARE. THE SBCCN, WHEN COMPLETED, WILL BUILD A SYSTEM THAT MONITORS, TRACKS, AND EVALUATES CARE PROVIDED IN SPINA BIFIDA CLINICS AND OTHER HEALTH CARE SETTINGS. THE SBCCN IS MADE UP OF PEOPLE OF DIFFERENT BACKGROUNDS AND EXPERIENCES: SPINA BIFIDA ASSOCIATION (SBA) STAFF, CHAPTER LEADERS, DOCTORS, NURSES, PSYCHOLOGISTS, THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC), PARENTS OF CHILDREN WITH SPINA BIFIDA, AND ADULTS WITH SPINA BIFIDA. THE ASSOCIATION WORKED IN CONJUNCTION WITH THE NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES TO CONTINUE RESEARCH THROUGH THE

4b (Code: ) (Expenses \$ 368,094. including grants of \$ 615. ) (Revenue \$ 36,489. ) EDUCATION - THE ASSOCIATION'S EDUCATION PROGRAMS PROVIDE PARENTS, CAREGIVERS AND PERSONS LIVING WITH SPINA BIFIDA WITH TOOLS AND RESOURCES AT CRITICAL POINTS IN DEVELOPMENT AND TRANSITION. EDUCATION AND INFORMATIONAL RESOURCES WERE PROVIDED TO OVER 325,000 PEOPLE WITH SPINA BIFIDA, PARENTS, AND CAREGIVERS AS WE CONTINUED TO EXPAND OUR REACH IN 2020 AS A RESULT OF INCORPORATING SOCIAL MEDIA.

4c (Code: ) (Expenses \$ 280,303. including grants of \$ 9,331. ) (Revenue \$ ) MEMBER SERVICES/CHAPTER DEVELOPMENT - THE ASSOCIATION PROMOTES THE GROWTH AND DEVELOPMENT OF ITS 16 CHAPTERS THROUGH TECHNICAL ASSISTANCE IN CAPACITY BUILDING, COMMUNICATIONS, PROGRAMMATIC RESOURCES AND GRANTS.

4d Other program services (Describe on Schedule O.) (Expenses \$ 197,896. including grants of \$ 553. ) (Revenue \$ )

4e Total program service expenses 1,544,925.

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Yes, No. Rows include questions 1 through 21 regarding organizational requirements and schedules.

COPY

**Part IV Checklist of Required Schedules** (continued)

	Yes	No
<b>22</b> Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i> .....	X	
<b>23</b> 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	
<b>24a</b> Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i> .....		X
<b>b</b> Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? .....		
<b>c</b> Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? .....		
<b>d</b> Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? .....		
<b>25a</b> <b>Section 501(c)(3), 501(c)(4), and 501(c)(29) 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>b</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
<b>26</b> Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part II</i> .....		X
<b>27</b> Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i> .....		X
<b>28</b> 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):		
<b>a</b> A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>b</b> A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>c</b> A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>29</b> Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> .....		X
<b>30</b> 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
<b>31</b> Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> .....		X
<b>32</b> 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
<b>33</b> 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
<b>34</b> 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
<b>35a</b> Did the organization have a controlled entity within the meaning of section 512(b)(13)? .....		X
<b>b</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> .....		
<b>36</b> <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
<b>37</b> 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
<b>38</b> Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? .....	X	

**Note:** All Form 990 filers are required to complete Schedule O

**Part V Statements Regarding Other IRS Filings and Tax Compliance**

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

	Yes	No
<b>1a</b> Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable .....		
<b>b</b> Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable .....		
<b>c</b> Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? .....	X	



Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

Table with columns for question number, question text, and Yes/No checkboxes. Includes questions 2a through 16 regarding employee counts, tax returns, business income, foreign accounts, prohibited transactions, and charitable contributions.

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 on Schedule O. See instructions.

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

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 13; 1b Enter the number of voting members included... 13; 2 Did any officer, director, trustee, or key employee have a family relationship... X; 3 Did the organization delegate control over management duties... X; 4 Did the organization make any significant changes to its governing documents... X; 5 Did the organization become aware during the year of a significant diversion of the organization's assets... X; 6 Did the organization have members or stockholders? X; 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? X; 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? X; 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a The governing body? X; 8b Each committee with authority to act on behalf of the governing body? X; 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O X

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? X; 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? X; 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? X; 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 X; 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? X; 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done X; 13 Did the organization have a written whistleblower policy? X; 14 Did the organization have a written document retention and destruction policy? X; 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? 15a The organization's CEO, Executive Director, or top management official X; 15b Other officers or key employees of the organization X; 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? X; 16b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed AL, AR, CA, FL, GA, IL, KS, KY, MD, MA, MI, MN
18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, 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. [X] Own website [X] Another's website [X] Upon request [ ] Other (explain on Schedule O)
19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records GLENRAE BROWN - (202) 944-3285 1600 WILSON BOULEVARD, NO. 800, ARLINGTON, VA 22209



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

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

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

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

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

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) SARA STRUWE PRESIDENT AND CEO	37.50			X			140,400.	0.	15,984.	
(2) GLENRAE BROWN CHIEF FINANCE OFFICER	37.50			X			110,250.	0.	15,869.	
(3) SHELIAH ROY CHIEF OPERATING OFFICER	37.50			X			100,000.	0.	732.	
(4) MICHAEL HARTY, JR. CHAIR	5.00	X		X			0.	0.	0.	
(5) NICOLE GOWER IMMEDIATE PAST CHAIR	2.00	X		X			0.	0.	0.	
(6) ANSHUL VARMA TREASURER/SECRETARY	2.00	X		X			0.	0.	0.	
(7) MARIA BOURNIAS, ESQ, CPA CHAIR-ELECT	2.00	X		X			0.	0.	0.	
(8) BRAD DICIANNO BOARD MEMBER	2.00	X					0.	0.	0.	
(9) NANCY GORE BOARD MEMBER	2.00	X					0.	0.	0.	
(10) DAVID MORRISSEY BOARD MEMBER	2.00	X					0.	0.	0.	
(11) WILSON NEYLAND BOARD MEMBER	2.00	X					0.	0.	0.	
(12) CHASE PHILLIPS BOARD MEMBER	2.00	X					0.	0.	0.	
(13) KATHRYN SMITH BOARD MEMBER	2.00	X					0.	0.	0.	
(14) MARIE THOMING BOARD MEMBER	2.00	X					0.	0.	0.	
(15) MCKAY TOLBOE BOARD MEMBER	2.00	X					0.	0.	0.	
(16) JOHN WIENER, MD BOARD MEMBER	2.00	X					0.	0.	0.	



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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
<b>1b Subtotal</b> .....							350,650.	0.	32,585.	
<b>c Total from continuation sheets to Part VII, Section A</b> .....							0.	0.	0.	
<b>d Total (add lines 1b and 1c)</b> .....							350,650.	0.	32,585.	

**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 **2**

	Yes	No
<b>3</b> Did the organization list any <b>former</b> officer, director, 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
NONE		

**2** Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization **0**





**Part VIII Statement of Revenue**

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

			(A)	(B)	(C)	(D)	
			Total revenue	Related or exempt function revenue	Unrelated business revenue	Revenue excluded from tax under sections 512 - 514	
Contributions, Gifts, Grants and Other Similar Amounts	<b>1 a</b>	Federated campaigns	<b>1a</b> 38,319.				
	<b>b</b>	Membership dues	<b>1b</b>				
	<b>c</b>	Fundraising events	<b>1c</b>				
	<b>d</b>	Related organizations	<b>1d</b>				
	<b>e</b>	Government grants (contributions)	<b>1e</b> 561,818.				
	<b>f</b>	All other contributions, gifts, grants, and similar amounts not included above	<b>1f</b> 859,891.				
	<b>g</b>	Noncash contributions included in lines 1a-1f	<b>1g</b> \$ 9,310.				
	<b>h</b>	<b>Total.</b> Add lines 1a-1f		1,460,028.			
Program Service Revenue	<b>2 a</b>	CONFERENCE & MEETINGS	Business Code 541800	37,489.	36,489.	1,000.	
	<b>b</b>						
	<b>c</b>						
	<b>d</b>						
	<b>e</b>						
	<b>f</b>	All other program service revenue					
	<b>g</b>	<b>Total.</b> Add lines 2a-2f		37,489.			
Other Revenue	<b>3</b>	Investment income (including dividends, interest, and other similar amounts)		14,227.		14,227.	
	<b>4</b>	Income from investment of tax-exempt bond proceeds					
	<b>5</b>	Royalties					
	<b>6 a</b>	Gross rents	(i) Real				
			(ii) Personal				
	<b>6 b</b>	Less: rental expenses					
	<b>6 c</b>	Rental income or (loss)					
	<b>d</b>	Net rental income or (loss)					
	<b>7 a</b>	Gross amount from sales of assets other than inventory	(i) Securities	343,991.			
			(ii) Other				
	<b>7 b</b>	Less: cost or other basis and sales expenses	335,214.				
	<b>7 c</b>	Gain or (loss)	8,777.				
<b>d</b>	Net gain or (loss)		8,777.		8,777.		
<b>8 a</b>	Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18						
<b>8 b</b>	Less: direct expenses						
<b>c</b>	Net income or (loss) from fundraising events						
<b>9 a</b>	Gross income from gaming activities. See Part IV, line 19						
<b>9 b</b>	Less: direct expenses						
<b>c</b>	Net income or (loss) from gaming activities						
<b>10 a</b>	Gross sales of inventory, less returns and allowances						
<b>10 b</b>	Less: cost of goods sold						
<b>c</b>	Net income or (loss) from sales of inventory						
Miscellaneous Revenue	<b>11 a</b>	REFUNDS	Business Code 900099	903.		903.	
	<b>b</b>	RESEARCH	900099	25.		25.	
	<b>c</b>						
	<b>d</b>	All other revenue					
	<b>e</b>	<b>Total.</b> Add lines 11a-11d		928.			
<b>12</b>	<b>Total revenue.</b> See instructions		1,521,449.	36,489.	0.	24,932.	

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**Part IX Statement of Functional Expenses**

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 ...	600.	600.		
2 Grants and other assistance to domestic individuals. See Part IV, line 22 .....	12,149.	12,149.		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 .....				
4 Benefits paid to or for members .....				
5 Compensation of current officers, directors, trustees, and key employees .....	382,835.	298,469.	84,366.	
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) .....				
7 Other salaries and wages .....	664,943.	492,435.	36,834.	135,674.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits .....	166,490.	120,171.	13,815.	32,504.
10 Payroll taxes .....	80,569.	69,297.	6,403.	4,869.
11 Fees for services (nonemployees):				
a Management .....				
b Legal .....				
c Accounting .....	46,881.	33,271.	9,029.	4,581.
d Lobbying .....	135,188.	135,188.		
e Professional fundraising services. See Part IV, line 17				
f Investment management fees .....	3,160.		3,160.	
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch. O.)	117,683.	92,329.	18,124.	7,230.
12 Advertising and promotion .....	721.	432.	188.	101.
13 Office expenses .....	206,881.	99,161.	36,146.	71,574.
14 Information technology .....	50,079.	45,226.	3,469.	1,384.
15 Royalties .....				
16 Occupancy .....	83,805.	66,024.	11,970.	5,811.
17 Travel .....	21,319.	19,796.	12.	1,511.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials ...				
19 Conferences, conventions, and meetings .....	33,730.	31,993.	681.	1,056.
20 Interest .....				
21 Payments to affiliates .....				
22 Depreciation, depletion, and amortization .....	29,831.	22,374.	3,579.	3,878.
23 Insurance .....				
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a <b>FILING REGISTRATION</b>	6,920.	1,623.	5,031.	266.
b <b>TAXES</b>	2,781.	1,537.	1,043.	201.
c <b>STAFF DEVELOPMENT</b>	2,612.	1,566.	680.	366.
d <b>SECURITY</b>	1,866.	1,119.	486.	261.
e All other expenses	353.	165.	9.	179.
<b>25 Total functional expenses.</b> Add lines 1 through 24e	<b>2,051,396.</b>	<b>1,544,925.</b>	<b>235,025.</b>	<b>271,446.</b>
<b>26 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)				

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**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash - non-interest-bearing .....	303,834.	<b>1</b>	236,118.
	<b>2</b> Savings and temporary cash investments .....	497,708.	<b>2</b>	441,369.
	<b>3</b> Pledges and grants receivable, net .....	111,088.	<b>3</b>	81,811.
	<b>4</b> Accounts receivable, net .....		<b>4</b>	
	<b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons .....		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) .....		<b>6</b>	
	<b>7</b> Notes and loans receivable, net .....		<b>7</b>	
	<b>8</b> Inventories for sale or use .....	5,139.	<b>8</b>	5,139.
	<b>9</b> Prepaid expenses and deferred charges .....	54,682.	<b>9</b>	43,501.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	<b>10a</b> 282,059.		
	<b>b</b> Less: accumulated depreciation .....	<b>10b</b> 219,691.	90,059.	<b>10c</b> 62,368.
	<b>11</b> Investments - publicly traded securities .....	616,838.	<b>11</b>	532,673.
	<b>12</b> Investments - other securities. See Part IV, line 11 .....		<b>12</b>	
	<b>13</b> Investments - program-related. See Part IV, line 11 .....		<b>13</b>	
	<b>14</b> Intangible assets .....		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11 .....	662.	<b>15</b>	662.
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) .....	1,680,010.	<b>16</b>	1,403,641.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses .....	85,775.	<b>17</b>	70,149.
	<b>18</b> Grants payable .....		<b>18</b>	
	<b>19</b> Deferred revenue .....	738.	<b>19</b>	15,744.
	<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 any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons .....		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties .....		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties .....		<b>24</b>	229,100.
	<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 .....	184,257.	<b>25</b>	178,553.
	<b>26 Total liabilities.</b> Add lines 17 through 25 .....	270,770.	<b>26</b>	493,546.
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions .....	1,097,206.	<b>27</b>	635,249.
	<b>28</b> Net assets with donor restrictions .....	312,034.	<b>28</b>	274,846.
	<b>Organizations that do not follow FASB ASC 958, check here</b> <input type="checkbox"/> <b>and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds .....		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building, or equipment fund .....		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds .....		<b>31</b>	
	<b>32</b> Total net assets or fund balances .....	1,409,240.	<b>32</b>	910,095.
<b>33</b> Total liabilities and net assets/fund balances .....	1,680,010.	<b>33</b>	1,403,641.	

**Part XI Reconciliation of Net Assets**

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,521,449.
2	Total expenses (must equal Part IX, column (A), line 25)	2	2,051,396.
3	Revenue less expenses. Subtract line 2 from line 1	3	-529,947.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,409,240.
5	Net unrealized gains (losses) on investments	5	30,802.
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	910,095.

**Part XII Financial Statements and Reporting**

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

- 1 Accounting method used to prepare the Form 990:  Cash  Accrual  Other \_\_\_\_\_  
If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.
- 2a Were the organization's financial statements compiled or reviewed by an independent accountant? .....  
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:  
 Separate basis  Consolidated basis  Both consolidated and separate basis
- 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:  
 Separate basis  Consolidated basis  Both consolidated and separate basis
- c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? .....  
If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.
- 3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? .....
- 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 on Schedule O and describe any steps taken to undergo such audits .....

	Yes	No
2a		X
2b	X	
2c	X	
3a		X
3b		

Form 990 (2020)

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

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

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

▶ Attach to Form 990 or Form 990-EZ.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2020**

Open to Public Inspection

<b>Name of the organization</b>	<b>Employer identification number</b>
SPINA BIFIDA ASSOCIATION OF AMERICA	58-1342181

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

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

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

f Enter the number of supported organizations .....

g Provide the following information about the supported organization(s).

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

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**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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	1467736.	1539962.	2905554.	1718305.	1460028.	9091585.
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....						
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....						
<b>4 Total.</b> Add lines 1 through 3 .....	1467736.	1539962.	2905554.	1718305.	1460028.	9091585.
<b>5</b> 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) .....						1051558.
<b>6 Public support.</b> Subtract line 5 from line 4.						8040027.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>7</b> Amounts from line 4 .....	1467736.	1539962.	2905554.	1718305.	1460028.	9091585.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....	8,927.	4,612.	4,043.	21,806.	14,227.	53,615.
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on .....						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....	826.			5.	25.	856.
<b>11 Total support.</b> Add lines 7 through 10						9146056.
<b>12</b> Gross receipts from related activities, etc. (see instructions) .....					12	896,335.
<b>13 First 5 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**

<b>14</b> Public support percentage for 2020 (line 6, column (f), divided by line 11, column (f)) .....	<b>14</b>	87.91 %
<b>15</b> Public support percentage from 2019 Schedule A, Part II, line 14 .....	<b>15</b>	88.44 %
<b>16a 33 1/3% support test - 2020.</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 - 2019.</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"/>
<b>17a 10% -facts-and-circumstances test - 2020.</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 VI 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 - 2019.</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 VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization .....		<input type="checkbox"/>
<b>18 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 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....						
<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 .....						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 .....						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....						
<b>6 Total.</b> Add lines 1 through 5 .....						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons .....						
<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 .....						
<b>c</b> Add lines 7a and 7b .....						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>9</b> Amounts from line 6 .....						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 .....						
<b>c</b> Add lines 10a and 10b .....						
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on .....						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.)						

**14 First 5 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 2020 (line 8, column (f), divided by line 13, column (f)) .....	<b>15</b>	%
<b>16</b> Public support percentage from 2019 Schedule A, Part III, line 15 .....	<b>16</b>	%

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

<b>17</b> Investment income percentage for 2020 (line 10c, column (f), divided by line 13, column (f)) .....	<b>17</b>	%
<b>18</b> Investment income percentage from 2019 Schedule A, Part III, line 17 .....	<b>18</b>	%

**19a 33 1/3% support tests - 2020.** 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 - 2019.** 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 Supporting Organizations**

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

**Section A. All Supporting Organizations**

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



**Part IV Supporting Organizations** (continued)

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

**Section B. Type I Supporting Organizations**

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

**Section C. Type II Supporting Organizations**

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

**Section D. All Type III Supporting Organizations**

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

**Section E. Type III Functionally Integrated Supporting Organizations**

<b>1</b> Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).		
<b>a</b> <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
<b>b</b> <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
<b>c</b> <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).		
<b>2</b> Activities Test. Answer lines 2a and 2b below.		
<b>a</b> Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>	Yes	No
<b>2a</b>		
<b>b</b> Did the activities described in line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
<b>2b</b>		
<b>3</b> Parent of Supported Organizations. Answer lines 3a and 3b below.		
<b>a</b> Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No" provide details in Part VI.</i>		
<b>3a</b>		
<b>b</b> Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		
<b>3b</b>		

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

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

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

Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	<b>Total</b> (add lines 1a, 1b, and 1c)	1d	
e	<b>Discount</b> claimed for blockage or other factors (explain in detail in Part VI):		
2	Acquisition indebtedness applicable to non-exempt-use assets	2	
3	Subtract line 2 from line 1d.	3	
4	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by 0.035.	6	
7	Recoveries of prior-year distributions	7	
8	<b>Minimum Asset Amount</b> (add line 7 to line 6)	8	

Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, column A)	1	
2	Enter 0.85 of line 1.	2	
3	Minimum asset amount for prior year (from Section B, line 8, column A)	3	
4	Enter greater of line 2 or line 3.	4	
5	Income tax imposed in prior year	5	
6	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6	
7	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

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

<b>Section D - Distributions</b>		<b>Current Year</b>
<b>1</b>	Amounts paid to supported organizations to accomplish exempt purposes	<b>1</b>
<b>2</b>	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	<b>2</b>
<b>3</b>	Administrative expenses paid to accomplish exempt purposes of supported organizations	<b>3</b>
<b>4</b>	Amounts paid to acquire exempt-use assets	<b>4</b>
<b>5</b>	Qualified set-aside amounts (prior IRS approval required - provide details in Part VI)	<b>5</b>
<b>6</b>	Other distributions (describe in Part VI). See instructions.	<b>6</b>
<b>7</b>	<b>Total annual distributions.</b> Add lines 1 through 6.	<b>7</b>
<b>8</b>	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	<b>8</b>
<b>9</b>	Distributable amount for 2020 from Section C, line 6	<b>9</b>
<b>10</b>	Line 8 amount divided by line 9 amount	<b>10</b>

<b>Section E - Distribution Allocations</b> (see instructions)	<b>(i) Excess Distributions</b>	<b>(ii) Underdistributions Pre-2020</b>	<b>(iii) Distributable Amount for 2020</b>
<b>1</b> Distributable amount for 2020 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2020 (reasonable cause required - explain in Part VI). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2020			
<b>a</b> From 2015			
<b>b</b> From 2016			
<b>c</b> From 2017			
<b>d</b> From 2018			
<b>e</b> From 2019			
<b>f</b> Total of lines 3a through 3e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2020 distributable amount			
<b>i</b> Carryover from 2015 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2020 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2020 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.			
<b>6</b> Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
<b>7</b> <b>Excess distributions carryover to 2021.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2016			
<b>b</b> Excess from 2017			
<b>c</b> Excess from 2018			
<b>d</b> Excess from 2019			
<b>e</b> Excess from 2020			

Schedule A (Form 990 or 990-EZ) 2020

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

**SCHEDULE A, PART II, LINE 10, EXPLANATION FOR OTHER INCOME:**

**MISCELLAENOUS**

2016 AMOUNT: \$ 826.

2017 AMOUNT: \$ 0.

2018 AMOUNT: \$ 0.

2019 AMOUNT: \$ 5.

2020 AMOUNT: \$ 25.

Multiple horizontal lines for providing additional information.

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**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.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2020**

Name of the organization

SPINA BIFIDA ASSOCIATION OF AMERICA

Employer identification number

58-1342181

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, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

**Special Rules**

For an organization described in section 501(c)(3) 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), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions 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 an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled 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. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year ..... ▶ \$ \_\_\_\_\_

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

Name of organization  <b>SPINA BIFIDA ASSOCIATION OF AMERICA</b>	Employer identification number  <b>58-1342181</b>
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**Part I Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	<hr/> <hr/> <hr/>	\$ <u>561,818.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	<hr/> <hr/> <hr/>	\$ <u>88,991.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	<hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	<hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	<hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	<hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	<hr/> <hr/> <hr/>	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

COPY

Name of organization  <b>SPINA BIFIDA ASSOCIATION OF AMERICA</b>	Employer identification number  <b>58-1342181</b>
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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
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____

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Name of organization  <b>SPINA BIFIDA ASSOCIATION OF AMERICA</b>	Employer identification number  <b>58-1342181</b>
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**Part III** Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. 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 info. once.) ▶ \$ \_\_\_\_\_  
Use duplicate copies of Part III if additional space is needed.

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

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

**Political Campaign and Lobbying Activities**

OMB No. 1545-0047

**2020**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

**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.**  
▶ **Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.**

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

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

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

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

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

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

Name of organization

**SPINA BIFIDA ASSOCIATION OF AMERICA**

Employer identification number

**58-1342181**

**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 campaign activity expenditures ..... ▶ \$ \_\_\_\_\_
- 3 Volunteer hours for political campaign activities .....

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

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

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

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

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

**For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.** **Schedule C (Form 990 or 990-EZ) 2020**

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

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

<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 (grassroots lobbying) .....	6,000.													
<b>b</b>	Total lobbying expenditures to influence a legislative body (direct lobbying) .....	135,188.													
<b>c</b>	Total lobbying expenditures (add lines 1a and 1b) .....	141,188.													
<b>d</b>	Other exempt purpose expenditures .....	1,913,048.													
<b>e</b>	Total exempt purpose expenditures (add lines 1c and 1d) .....	2,054,236.													
<b>f</b>	Lobbying nontaxable amount. Enter the amount from the following table in both columns.	252,712.													
<table border="1" style="width: 100%; border-collapse: collapse;"> <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) .....	63,178.													
<b>h</b>	Subtract line 1g from line 1a. If zero or less, enter -0- .....	0.													
<b>i</b>	Subtract line 1f from line 1c. If zero or less, enter -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 separate instructions for lines 2a through 2f.)

<b>Lobbying Expenditures During 4-Year Averaging Period</b>					
Calendar year (or fiscal year beginning in)	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) Total
<b>2a</b> Lobbying nontaxable amount	241,050.	241,876.	261,515.	252,712.	997,153.
<b>b</b> Lobbying ceiling amount (150% of line 2a, column(e))					1,495,730.
<b>c</b> Total lobbying expenditures	57,620.	168,659.	206,315.	141,188.	573,782.
<b>d</b> Grassroots nontaxable amount	60,263.	60,469.	65,379.	63,178.	249,289.
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					373,934.
<b>f</b> Grassroots lobbying expenditures	3,844.	6,000.	6,000.	6,000.	21,844.

Schedule C (Form 990 or 990-EZ) 2020

COPY

**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)).**

	(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 .....			
<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? .....	<b>1</b>	
<b>2</b> Did the organization make only in-house lobbying expenditures of \$2,000 or less? .....	<b>2</b>	
<b>3</b> Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? .....	<b>3</b>	

**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>
<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>

**Part IV Supplemental Information**

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

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SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

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

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization SPINA BIFIDA ASSOCIATION OF AMERICA Employer identification number 58-1342181

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, grants, and end of year, and two yes/no questions about donor property and grant fund usage.

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include purpose of easements, a table for lines 2a-2d (Total number, acreage, certified historic structures, acquired after 7/25/06), and questions about monitoring, staff hours, expenses, and reporting requirements.

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include questions about reporting requirements for art and historical treasures, and a table for revenue and assets included.

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule D (Form 990) 2020

**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 make 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 program
  - e  Other \_\_\_\_\_
- 4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?  Yes  No

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

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

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	64,564.	62,552.	62,563.	61,087.	59,862.
b Contributions					
c Net investment earnings, gains, and losses	3,339.	2,012.	-11.	1,476.	1,225.
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance	67,903.	64,564.	62,552.	62,563.	61,087.

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment  88.3600 %
  - b Permanent endowment  .0000 %
  - c Term endowment  11.6400 %
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- |   | Yes                      | No                                  |
|---|--------------------------|-------------------------------------|
| (i) Unrelated organizations   | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| (ii) Related organizations  | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            |
- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

**Part VI Land, Buildings, and Equipment.**

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements		128,355.	96,269.	32,086.
d Equipment		62,660.	53,709.	8,951.
e Other		91,044.	69,713.	21,331.
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				62,368.

**Part VII Investments - Other Securities.**

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

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

**Part VIII Investments - Program Related.**

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

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

**Part IX Other Assets.**

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

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

**Part X Other Liabilities.**

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) DEFERRED RENT AND LEASEHOLD	
(3) INCENTIVES	178,553.
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	178,553.

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

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

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

1	Total revenue, gains, and other support per audited financial statements		1	1,560,034.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	30,802.	
b	Donated services and use of facilities	2b	10,943.	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e		41,745.
3	Subtract line 2e from line 1	3		1,518,289.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	3,160.	
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		3,160.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5		1,521,449.

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

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

1	Total expenses and losses per audited financial statements		1	2,059,179.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	10,943.	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e		10,943.
3	Subtract line 2e from line 1	3		2,048,236.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	3,160.	
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		3,160.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	5		2,051,396.

**Part XIII Supplemental Information.**

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

**PART V, LINE 4:**

THE ENDOWMENT FUNDS ARE USED TO FUND SCHOLARSHIPS FOR PEOPLE WITH SPINA BIFIDA, FUND GRANTS TO PROMOTE THE PREVENTION AND CURE OF SPINA BIFIDA, AND TO IMPROVE THE LIVES OF THOSE LIVING WITH SPINA BIFIDA.

**PART X, LINE 2:**

THE ASSOCIATION EVALUATED ITS UNCERTAINTY IN INCOME TAXES FOR THE YEAR ENDED DECEMBER 31, 2020, AND DETERMINED THAT THERE WERE NO MATTERS THAT WOULD REQUIRE RECOGNITION IN THE FINANCIAL STATEMENTS OR THAT MAY HAVE ANY EFFECT ON ITS TAX-EXEMPT STATUS.



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

Multiple horizontal lines for supplemental information.

**COPY**



**SCHEDULE I  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

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

▶ **Attach to Form 990.**

▶ **Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.**

OMB No. 1545-0047

**2020**

**Open to Public  
Inspection**

Name of the organization **SPINA BIFIDA ASSOCIATION OF AMERICA** Employer identification number **58-1342181**

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

<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 noncash assistance	<b>(h)</b> Purpose of grant or assistance

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

**3** Enter total number of other organizations listed in the line 1 table ..... ▶ \_\_\_\_\_

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

Schedule I (Form 990) 2020

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

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
CHAPTER SCHOLARSHIPS & AWARDS	14	7,961.	0.		
EMERGENCY ASSISTANCE AWARDS	3	1,000.	0.		
DEVELOPMENT AWARDS	5	220.	0.		
EDUCATION OUTREACH	9	45.	0.		
RESEARCH AWARDS	20	200.	0.		

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

PART I, LINE 2:

THE ASSOCIATION PERFORMS A FINANCIAL AND PROGRAM REVIEW FOR EACH GRANT  
DISBURSEMENT TO ENSURE THAT SUCH GRANTS ARE USED FOR PROPER PURPOSES AND  
ARE NOT OTHERWISE DIVERTED FROM THE INTENDED USE.

Part III Continuation of Grants and Other Assistance to Domestic Individuals (Schedule I (Form 990), Part III.)

(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 noncash assistance
SB-YOU AWARDS	20.	420.	0.		
CLINICAL CARE PARTNER AWARDS	32.	2,050.	0.		
ADVOCACY AWARDS	2.	253.	0.		

**SCHEDULE J  
(Form 990)**

**Compensation Information**

OMB No. 1545-0047

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

**2020**

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

▶ Attach to Form 990.

Open to Public Inspection

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

Department of the Treasury  
Internal Revenue Service

Name of the organization

**SPINA BIFIDA ASSOCIATION OF AMERICA**

Employer identification number

**58-1342181**

**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 on 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 (such as 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 directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a? .....

**3** Indicate which, if any, of the following the 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 checked="" type="checkbox"/> Compensation survey or study                    |
| <input type="checkbox"/> Form 990 of other organizations     | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

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

- a** Receive a severance payment or change-of-control payment? .....
- 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), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.**

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

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

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

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

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

**8** Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III .....

**9** If "Yes" on 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>		<b>X</b>
<b>4b</b>		<b>X</b>
<b>4c</b>		<b>X</b>
<b>5a</b>		<b>X</b>
<b>5b</b>		<b>X</b>
<b>6a</b>		<b>X</b>
<b>6b</b>		<b>X</b>
<b>7</b>		<b>X</b>
<b>8</b>		<b>X</b>
<b>9</b>		

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

Schedule J (Form 990) 2020

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

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

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

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
(1) SARA STRUWE PRESIDENT AND CEO	(i)	140,400.	0.	0.	0.	15,984.	156,384.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							



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

Department of the Treasury  
Internal Revenue Service

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

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

▶ Attach to Form 990 or 990-EZ.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2020**

Open to Public  
Inspection

Name of the organization

SPINA BIFIDA ASSOCIATION OF AMERICA

Employer identification number

58-1342181

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

THE SPINA BIFIDA ASSOCIATION IS TO BUILD A BETTER AND BRIGHTER FUTURE  
FOR ALL THOSE IMPACTED BY SPINA BIFIDA.

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

EDUCATE AND TRAIN THE PROFESSIONALS INVOLVED IN THE TREATMENT OF SPINA  
BIFIDA.

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

NATIONAL SPINA BIFIDA PATIENT REGISTRY (NSBPR). THE SPINA BIFIDA  
COLLABORATIVE CARE NETWORK PRODUCED GUIDELINES FOR THE CARE OF PEOPLE  
LIVING WITH SPINA BIFIDA WHICH INCLUDED RESEARCH FROM THE NSBPR.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:

GOVERNMENT RELATIONS

EXPENSES \$ 146,974. INCLUDING GRANTS OF \$ 403. REVENUE \$ 0.

INFORMATION AND REFERRAL

EXPENSES \$ 50,922. INCLUDING GRANTS OF \$ 150. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 6:

EACH CHAPTER OF THE ASSOCIATION WHICH MEETS THE AFFILIATION STANDARDS OF  
THE ASSOCIATION AND IS IN GOOD STANDING AT THE TIME OF EACH RELEVANT  
MEETING IS REFERRED TO AS A MEMBER.

FORM 990, PART VI, SECTION A, LINE 7A:

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

Schedule O (Form 990 or 990-EZ) 2020

032211 11-20-20

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DELEGATES ARE APPOINTED BY EACH CHAPTER. THESE DELEGATES APPROVE THE NEW MEMBERS OF THE BOARD OF DIRECTORS AND THE SLATE OF OFFICERS OF THE BOARD.

FORM 990, PART VI, SECTION A, LINE 7B:

ANY CHANGES IN THE ASSOCIATION'S BYLAWS AND ARTICLES OF INCORPORATION ARE REQUIRED TO BE APPROVED BY A MAJORITY OF THE CHAPTER DELEGATES PRESENT AT THE ANNUAL BOARD MEETING.

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

THE DRAFT VERSION OF THE FEDERAL FORM 990 IS REVIEWED BY THE PRESIDENT AND CEO AS WELL AS THE CHIEF FINANCIAL OFFICER. IT IS THEN IS GIVEN TO THE AUDIT COMMITTEE FOR REVIEW, DISCUSSION AND APPROVAL. A COPY OF THE DRAFT FEDERAL FORM 990 IS PROVIDED TO THE ENTIRE BOARD OF DIRECTORS PRIOR TO FILING WITH THE INTERNAL REVENUE SERVICE.

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

ANNUAL WRITTEN CONFIRMATION IS REQUIRED FROM ALL BOARD MEMBERS WHO IDENTIFY ANY POTENTIAL CONFLICTS OF INTEREST. THE CONFIRMATION FORM STATES THAT BOARD MEMBERS FOR WHOM THERE IS A CONFLICT ON A GIVEN ISSUE WILL NOT BE INVOLVED IN ANY DISCUSSIONS NOR VOTES ON AREAS OF CONFLICT. THE ANNUAL CONFLICT OF INTEREST (COI) STATEMENTS ARE REVIEWED BY THE BOARD CHAIR AND THE CEO AND, IF ANY COI ITEMS ARE IDENTIFIED, THEY WILL BE BROUGHT TO THE BOARD FOR REVIEW. IN ADDITION, BOARD MEMBERS ARE EXPECTED TO IDENTIFY ANY POTENTIAL CONFLICTS THAT MAY ARISE THROUGHOUT THE YEAR AND AFTER THE COI STATEMENTS ARE SIGNED.

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

THERE IS A FORMAL REVIEW OF THE CHIEF EXECUTIVE OFFICER'S (CEO)



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COMPENSATION BY THE BOARD OF DIRECTORS. A FORMAL REVIEW IS MADE BY THE CEO FOR ALL OTHER EMPLOYEES. THE BOARD OF DIRECTORS EMPLOYS A COMBINATION OF PERFORMANCE EVALUATION AND REVIEW OF BOTH LOCAL AND NATIONAL COMPENSATION SURVEYS TO ESTABLISH THE COMPENSATION OF THE CEO. SIMILARLY, THE CEO EMPLOYS PERFORMANCE REVIEWS AND DOCUMENTATION ON REGIONAL COMPENSATION STUDIES TO REVIEW ALL STAFF INCLUDING THE CONTROLLER. ALL STAFF PERFORMANCE REVIEWS AND COMPENSATION CHANGES ARE PRESENTED TO THE CEO PRIOR TO FINALIZING FOR WRITTEN APPROVAL. THE COMPENSATION STUDY LAST TOOK PLACE DURING DECEMBER 2019.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:  
AL, AR, CA, FL, GA, IL, KS, KY, MD, MA, MI, MN, MS, NH, NJ, NM, NY, NC, OK, OR, PA, RI, SC, TN, UT  
VA, WI, WV

FORM 990, PART VI, SECTION C, LINE 19:  
THE ASSOCIATION MAKES ITS GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY, AND FINANCIAL STATEMENTS AVAILABLE TO THE PUBLIC ON THEIR WEBSITE.

FORM 990, PART I, LINE 5 & PART V, LINE 2A  
THE ASSOCIATION HAS CONTRACTED WITH A PROFESSIONAL EMPLOYER ORGANIZATION, ADP TOTALSOURCE, TO SERVE AS THE EMPLOYER OF RECORD FOR THE ASSOCIATION'S EMPLOYEES. AS SUCH, ADP TOTALSOURCE IS RESPONSIBLE FOR TAX FILINGS RELATED TO EMPLOYEES. ADP TOTALSOURCE ISSUED 14 W-2 FORMS IN 2020 FOR ASSOCIATION EMPLOYEES.

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