

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

Form 990

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

2023

Department of the Treasury Internal Revenue Service

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

Open to Public Inspection

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

A For the 2023 calendar year, or tax year beginning and ending

B Check if applicable: C Name of organization: SPINA BIFIDA ASSOCIATION OF AMERICA D Employer identification number: \*\* - \*\*\*2181 E Telephone number: 202-618-4750 G Gross receipts \$: 3,458,122. H(a) Is this a group return for subordinates? H(b) Are all subordinates included? I Tax-exempt status: J Website: K Form of organization: L Year of formation: M State of legal domicile:

Part I Summary

Table with columns for Activities & Governance, Revenue, Expenses, and Net Assets or Fund Balances. Rows include mission statement, member counts, revenue breakdown, expenses, and net assets.

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 SARA STRUWE, PRESIDENT AND CEO, Date 10/25/2024. Paid Preparer: ADRIEL HENRIQUEZ BAIREZ, RENNER AND COMPANY CPA, P.C., Date 10/25/24, PTIN P01822536.

May the IRS discuss this return with the preparer shown above? See instructions. [X] Yes [ ] No

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: 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 \$ 691,263. including grants of \$ ) (Revenue \$ 331,360. ) 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, PSYCHOLOGIST, 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 \$ 1,272,520. including grants of \$ ) (Revenue \$ ) 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 2022 AS A RESULT OF INCORPORATING SOCIAL MEDIA.

4c (Code: ) (Expenses \$ 448,594. including grants of \$ ) (Revenue \$ ) CHAPTER DEVELOPMENT THE ASSOCIATION PROMOTES THE GROWTH AND DEVELOPMENT OF ITS 14 CHAPTERS THROUGH TECHNICAL ASSISTANCE IN CAPACITY BUILDING, COMMUNICATIONS, PROGRAMMATIC RESOURCES AND GRANTS.

4d Other program services (Describe on Schedule O.) (Expenses \$ 272,920. including grants of \$ ) (Revenue \$ 330,443.)

4e Total program service expenses 2,685,297.

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 A through I.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 22 through 38 regarding grants, compensation, tax-exempt bonds, excess benefits, and controlled entities.

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and backup withholding rules.

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

Table with columns for question number, question text, and Yes/No columns. Includes questions 2a through 17 regarding employee counts, tax returns, gross 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 (14), 1b (14), 2, 3, 4, 5, 6, 7a, 7b, 8a, 8b, 9.

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

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

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed AL, 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.
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

**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 the 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, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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 the 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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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			141,598.	0.	21,879.	
(2) GLENRAE BROWN CHIEF FINANCIAL OFFICER	37.50			X			114,488.	0.	21,709.	
(3) MICHAEL WOOD CHIEF OPERATING OFFICER	37.50			X			113,221.	0.	21,709.	
(4) MARIA BOURNIAS, ESQ, CPA CHAIR	5.00	X		X			0.	0.	0.	
(5) MICHAEL HARTY, JR IMMEDIATE PAST CHAIR	2.00	X		X			0.	0.	0.	
(6) NANCY GORE CHAIR-ELECT	2.00	X		X			0.	0.	0.	
(7) ANSHUL VARMA SECRETARY/TREASURER	2.00	X		X			0.	0.	0.	
(8) ROBIN M BOWMAN, MD DIRECTOR	2.00	X					0.	0.	0.	
(9) DOUG BURNS DIRECTOR	2.00	X					0.	0.	0.	
(10) ELLEN FREMION, MD, FAAP, FACP DIRECTOR	2.00	X					0.	0.	0.	
(11) TRACY DINUNZIO DIRECTOR	2.00	X					0.	0.	0.	
(12) CHASE PHILLIPS DIRECTOR	2.00	X					0.	0.	0.	
(13) KATHRYN ANN NAVARETTE SMITH, RN DIRECTOR	2.00	X					0.	0.	0.	
(14) ERIC TOBIN DIRECTOR	2.00	X					0.	0.	0.	
(15) BRYAN VODICKA DIRECTOR	2.00	X					0.	0.	0.	
(16) DAWNE WIDENER-BURROWS DIRECTOR	2.00	X					0.	0.	0.	
(17) JOHN WIENER, MD DIRECTOR	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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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> .....							369,307.	0.	65,297.	
<b>c Total from continuation sheets to Part VII, Section A</b> .....							0.	0.	0.	
<b>d Total (add lines 1b and 1c)</b> .....							369,307.	0.	65,297.	

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

	Yes	No
<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
LOEWS HOTEL & CO FINANCIAL SVS LVC HOTEL LL 455 DUKE DRIVE SUITE 103, FRANKLIN, TN 3706	CONFERENCE HOTEL	240,953.
DAVINCI DIRECT INC P.O. BOX 1640, PLYMOUTH, MA 02362	FUNDRAISING CONSULTANT	130,229.
VENABLE LLP P.O. BOX 62727, BALTIMORE, MD 21264	GOVERNMENT RELATIONS CONSULTANT	108,500.

**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 3



**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> 70,003.					
	<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> 921,475.					
	<b>f</b>	All other contributions, gifts, grants, and similar amounts not included above ...	<b>1f</b> 1,151,123.					
	<b>g</b>	Noncash contributions included in lines 1a-1f	<b>1g</b> \$					
	<b>h</b>	<b>Total.</b> Add lines 1a-1f .....						2,142,601.
Program Service Revenue	<b>2 a</b>	CONFERENCE AND MEETIN	Business Code 541800	331,360.	331,360.			
	<b>b</b>	SPECIAL EVENTS	900099	292,329.	292,329.			
	<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 .....			623,689.			
Other Revenue	<b>3</b>	Investment income (including dividends, interest, and other similar amounts) .....		15,488.			15,488.	
	<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>b</b>	Less: rental expenses ...	<b>6b</b>					
	<b>c</b>	Rental income or (loss)	<b>6c</b>					
	<b>d</b>	Net rental income or (loss) .....						
	<b>7 a</b>	Gross amount from sales of assets other than inventory .....	(i) Securities					
			(ii) Other					
	<b>b</b>	Less: cost or other basis and sales expenses .....	<b>7b</b> 623,612.					
<b>c</b>	Gain or (loss) .....	<b>7c</b> 14,618.						
<b>d</b>	Net gain or (loss) .....			14,618.			14,618.	
<b>8 a</b>	Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18 .....	<b>8a</b>						
<b>b</b>	Less: direct expenses .....	<b>8b</b>						
<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>9a</b>						
<b>b</b>	Less: direct expenses .....	<b>9b</b>						
<b>c</b>	Net income or (loss) from gaming activities .....							
<b>10 a</b>	Gross sales of inventory, less returns and allowances .....	<b>10a</b>						
<b>b</b>	Less: cost of goods sold .....	<b>10b</b>						
<b>c</b>	Net income or (loss) from sales of inventory .....							
Miscellaneous Revenue	<b>11 a</b>	OTHER INCOME	Business Code 900099	38,114.	38,114.			
	<b>b</b>							
	<b>c</b>							
	<b>d</b>	All other revenue .....						
	<b>e</b>	<b>Total.</b> Add lines 11a-11d .....			38,114.			
<b>12</b>	<b>Total revenue.</b> See instructions .....			2,834,510.	661,803.	0.	30,106.	

**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  X

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
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 ...				
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22 .....				
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 .....				
<b>4</b> Benefits paid to or for members .....				
<b>5</b> Compensation of current officers, directors, trustees, and key employees .....	441,149.	365,978.	21,737.	53,434.
<b>6</b> Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) .....				
<b>7</b> Other salaries and wages .....	757,510.	634,197.	37,561.	85,752.
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
<b>9</b> Other employee benefits .....	260,073.	209,541.	12,359.	38,173.
<b>10</b> Payroll taxes .....	108,394.	90,373.	5,562.	12,459.
<b>11</b> Fees for services (nonemployees):				
<b>a</b> Management .....				
<b>b</b> Legal .....				
<b>c</b> Accounting .....	75,927.		75,927.	
<b>d</b> Lobbying .....	47,956.	47,956.		
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees .....	1,780.		1,780.	
<b>g</b> Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.)	675,164.	661,265.	7,230.	6,669.
<b>12</b> Advertising and promotion .....	4,306.	4,306.		
<b>13</b> Office expenses .....	163,485.	137,115.	8,849.	17,521.
<b>14</b> Information technology .....	2,698.	2,224.	237.	237.
<b>15</b> Royalties .....				
<b>16</b> Occupancy .....	32,479.	22,088.	6,231.	4,160.
<b>17</b> Travel .....	127,187.	119,880.	2,109.	5,198.
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials ...				
<b>19</b> Conferences, conventions, and meetings .....	324,687.	323,766.	542.	379.
<b>20</b> Interest .....				
<b>21</b> Payments to affiliates .....				
<b>22</b> Depreciation, depletion, and amortization .....	7,359.		7,359.	
<b>23</b> Insurance .....	11,549.	8,057.	1,746.	1,746.
<b>24</b> 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.)				
<b>a</b> <b>BANK FEES</b>	48,243.	28,952.	9,710.	9,581.
<b>b</b> <b>MISCELLANEOUS</b>	43,614.	1,379.	42,069.	166.
<b>c</b> <b>EQUIPMENT RENTAL AND MA</b>	22,016.	15,991.	2,986.	3,039.
<b>d</b> <b>FILING REGISTRATION</b>	8,693.	6,718.	320.	1,655.
<b>e</b> All other expenses .....	11,281.	5,511.	5,352.	418.
<b>25</b> <b>Total functional expenses.</b> Add lines 1 through 24e	3,175,550.	2,685,297.	249,666.	240,587.
<b>26</b> <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

**Part X Balance Sheet**

Check if Schedule O contains a response 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 .....	297,686.	<b>1</b>	298,258.
	<b>2</b> Savings and temporary cash investments .....	292,412.	<b>2</b>	
	<b>3</b> Pledges and grants receivable, net .....	193,502.	<b>3</b>	225,711.
	<b>4</b> Accounts receivable, net .....		<b>4</b>	21,774.
	<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 .....		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges .....	126,268.	<b>9</b>	36,941.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	<b>10a</b> 233,328.		
	<b>b</b> Less: accumulated depreciation .....	<b>10b</b> 230,896.		
	<b>11</b> Investments - publicly traded securities .....	440,670.	<b>11</b>	401,165.
	<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 .....	58,320.	<b>15</b>	33,227.
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) .....	1,417,977.	<b>16</b>	1,019,508.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses .....	73,910.	<b>17</b>	192,466.
	<b>18</b> Grants payable .....		<b>18</b>	
	<b>19</b> Deferred revenue .....	151,928.	<b>19</b>	20,890.
	<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>	
	<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 .....	177,914.	<b>25</b>	102,112.
	<b>26 Total liabilities.</b> Add lines 17 through 25 .....	403,752.	<b>26</b>	315,468.
<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 .....	774,316.	<b>27</b>	360,402.
	<b>28</b> Net assets with donor restrictions .....	239,909.	<b>28</b>	343,638.
	<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 .....	1,014,225.	<b>32</b>	704,040.
	<b>33</b> Total liabilities and net assets/fund balances .....	1,417,977.	<b>33</b>	1,019,508.

**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	2,834,510.
2	Total expenses (must equal Part IX, column (A), line 25)	2	3,175,550.
3	Revenue less expenses. Subtract line 2 from line 1	3	-341,040.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,014,225.
5	Net unrealized gains (losses) on investments	5	30,855.
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	704,040.

**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 on 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 Uniform Guidance, 2 C.F.R. Part 200, Subpart F? .....
- 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
1		
2a		X
b	X	
c	X	
3a	X	
3b	X	

Form 990 (2023)

**SCHEDULE A**  
**(Form 990)**

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

**2023**

Open to Public Inspection

Name of the organization <b>SPINA BIFIDA ASSOCIATION OF AMERICA</b>	Employer identification number <b>**-***2181</b>
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**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).)
- 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 on 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>						

**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) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	1718305.	1460028.	2139236.	2092167.	2142601.	9552337.
<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 .....	1718305.	1460028.	2139236.	2092167.	2142601.	9552337.
<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) .....						
<b>6 Public support.</b> Subtract line 5 from line 4.						9552337.

**Section B. Total Support**

Calendar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
<b>7</b> Amounts from line 4 .....	1718305.	1460028.	2139236.	2092167.	2142601.	9552337.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....	21,806.	14,227.	7,879.	1,808.	15,488.	61,208.
<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.) .....	25.	8,850.	20,114.	28,995.	38,114.	96,098.
<b>11 Total support.</b> Add lines 7 through 10						9709643.
<b>12</b> Gross receipts from related activities, etc. (see instructions) .....					12	331,360.
<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 2023 (line 6, column (f), divided by line 11, column (f)) .....	<b>14</b>	98.38	%
<b>15</b> Public support percentage from 2022 Schedule A, Part II, line 14 .....	<b>15</b>	98.97	%
<b>16a 33 1/3% support test - 2023.</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 - 2022.</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 - 2023.</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 - 2022.</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

Table with 7 columns: (a) 2019, (b) 2020, (c) 2021, (d) 2022, (e) 2023, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 8 Public support.

Section B. Total Support

Table with 7 columns: (a) 2019, (b) 2020, (c) 2021, (d) 2022, (e) 2023, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 10c Add lines 10a and 10b; 11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on; 12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.); 13 Total support.

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

Table with 2 columns: Description, Percentage. Row 15: Public support percentage for 2023 (line 8, column (f), divided by line 13, column (f)) 15%. Row 16: Public support percentage from 2022 Schedule A, Part III, line 15 16%.

Section D. Computation of Investment Income Percentage

Table with 2 columns: Description, Percentage. Row 17: Investment income percentage for 2023 (line 10c, column (f), divided by line 13, column (f)) 17%. Row 18: Investment income percentage from 2022 Schedule A, Part III, line 17 18%.

19a 33 1/3% support tests - 2023. 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 - 2022. 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 on line 12 of 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).</i>		
<b>8</b> Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</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 on 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 on 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)

Table with 3 columns: Question, Yes, No. Contains questions 11a, 11b, 11c regarding gift acceptance.

Section B. Type I Supporting Organizations

Table with 3 columns: Question, Yes, No. Contains questions 1 and 2 regarding governing body powers and organization benefits.

Section C. Type II Supporting Organizations

Table with 3 columns: Question, Yes, No. Contains question 1 regarding directors/trustees.

Section D. All Type III Supporting Organizations

Table with 3 columns: Question, Yes, No. Contains questions 1, 2, 3 regarding support provided, officers, and significant voice.

Section E. Type III Functionally Integrated Supporting Organizations

Table with 3 columns: Question, Yes, No. Contains questions 1-3 regarding the Integral Part Test and Activities Test.

**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 ( <i>explain in detail in Part VI</i> ):		
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)

Section D - Distributions		Current Year
1	Amounts paid to supported organizations to accomplish exempt purposes	1
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2
3	Administrative expenses paid to accomplish exempt purposes of supported organizations	3
4	Amounts paid to acquire exempt-use assets	4
5	Qualified set-aside amounts (prior IRS approval required - <i>provide details in Part VI</i> )	5
6	Other distributions ( <i>describe in Part VI</i> ). See instructions.	6
7	<b>Total annual distributions.</b> Add lines 1 through 6.	7
8	Distributions to attentive supported organizations to which the organization is responsive ( <i>provide details in Part VI</i> ). See instructions.	8
9	Distributable amount for 2023 from Section C, line 6	9
10	Line 8 amount divided by line 9 amount	10

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2023	(iii) Distributable Amount for 2023
1	Distributable amount for 2023 from Section C, line 6		
2	Underdistributions, if any, for years prior to 2023 (reasonable cause required - <i>explain in Part VI</i> ). See instructions.		
3	Excess distributions carryover, if any, to 2023		
a	From 2018		
b	From 2019		
c	From 2020		
d	From 2021		
e	From 2022		
f	<b>Total</b> of lines 3a through 3e		
g	Applied to underdistributions of prior years		
h	Applied to 2023 distributable amount		
i	Carryover from 2018 not applied (see instructions)		
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.		
4	Distributions for 2023 from Section D, line 7: \$		
a	Applied to underdistributions of prior years		
b	Applied to 2023 distributable amount		
c	Remainder. Subtract lines 4a and 4b from line 4.		
5	Remaining underdistributions for years prior to 2023, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions.		
6	Remaining underdistributions for 2023. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.		
7	<b>Excess distributions carryover to 2024.</b> Add lines 3j and 4c.		
8	Breakdown of line 7:		
a	Excess from 2019		
b	Excess from 2020		
c	Excess from 2021		
d	Excess from 2022		
e	Excess from 2023		

Schedule A (Form 990) 2023

**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.)

Horizontal lines for supplemental information input.

SCHEDULE C
(Form 990)

Political Campaign and Lobbying Activities

OMB No. 1545-0047

2023

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 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: \*\* - \*\*\* 2181

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.

Table with 5 columns: (a) Name, (b) Address, (c) EIN, (d) Amount paid from filing organization's funds, (e) Amount of political contributions received and promptly and directly delivered to a separate political organization.

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

Schedule C (Form 990) 2023

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

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

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)	(a) Filing organization's totals	(b) Affiliated group totals												
<b>1a</b> Total lobbying expenditures to influence public opinion (grassroots lobbying) .....	45,686.													
<b>b</b> Total lobbying expenditures to influence a legislative body (direct lobbying) .....	159,496.													
<b>c</b> Total lobbying expenditures (add lines 1a and 1b) .....	205,182.													
<b>d</b> Other exempt purpose expenditures .....	2,968,588.													
<b>e</b> Total exempt purpose expenditures (add lines 1c and 1d) .....	3,173,770.													
<b>f</b> Lobbying nontaxable amount. Enter the amount from the following table in both columns.	308,689.													
<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 30%; text-align: left;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width: 70%; text-align: left;">The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>not over \$500,000,</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>over \$500,000 but not over \$1,000,000,</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>over \$1,000,000 but not over \$1,500,000,</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>over \$1,500,000 but not over \$17,000,000,</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>over \$17,000,000,</td> <td>\$1,000,000.</td> </tr> </tbody> </table>	If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	not over \$500,000,	20% of the amount on line 1e.	over \$500,000 but not over \$1,000,000,	\$100,000 plus 15% of the excess over \$500,000.	over \$1,000,000 but not over \$1,500,000,	\$175,000 plus 10% of the excess over \$1,000,000.	over \$1,500,000 but not over \$17,000,000,	\$225,000 plus 5% of the excess over \$1,500,000.	over \$17,000,000,	\$1,000,000.		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:													
not over \$500,000,	20% of the amount on line 1e.													
over \$500,000 but not over \$1,000,000,	\$100,000 plus 15% of the excess over \$500,000.													
over \$1,000,000 but not over \$1,500,000,	\$175,000 plus 10% of the excess over \$1,000,000.													
over \$1,500,000 but not over \$17,000,000,	\$225,000 plus 5% of the excess over \$1,500,000.													
over \$17,000,000,	\$1,000,000.													
<b>g</b> Grassroots nontaxable amount (enter 25% of line 1f) .....	77,172.													
<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.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) Total
<b>2a</b> Lobbying nontaxable amount	252,712.	251,651.	265,291.	308,689.	1,078,343.
<b>b</b> Lobbying ceiling amount (150% of line 2a, column(e))					1,617,515.
<b>c</b> Total lobbying expenditures	141,188.	159,288.	75,988.	205,182.	581,646.
<b>d</b> Grassroots nontaxable amount	63,178.	62,913.	66,323.	77,172.	269,586.
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					404,379.
<b>f</b> Grassroots lobbying expenditures	6,000.	5,775.	30,659.	45,686.	88,120.

Schedule C (Form 990) 2023

**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 not be 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 expenditures 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

2023

Open to Public Inspection

Name of the organization SPINA BIFIDA ASSOCIATION OF AMERICA Employer identification number \*\* - \*\*\* 2181

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, details of conservation contributions (lines 2a-2d), number of modified easements, states where located, monitoring policy, staff hours, expenses, and requirements for section 170(h)(4)(B)(i) and (ii).

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 art and historical treasures (1a, 1b) and amounts for revenue and assets (2a, 2b).

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule D (Form 990) 2023



**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 in Part XIII

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	239,909.	241,479.	274,846.	312,034.	341,658.
b Contributions	242,096.	60,080.			
c Net investment earnings, gains, and losses	8,771.	-4,119.	3,232.	3,339.	2,012.
d Grants or scholarships					
e Other expenditures for facilities and programs	147,138.	57,531.	36,599.	40,527.	31,636.
f Administrative expenses					
g End of year balance	343,638.	239,909.	241,479.	274,846.	312,034.

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment \_\_\_\_\_%
  - b Permanent endowment 17.4600 %
  - c Term endowment 82.5400 %
- 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?   |     | X  |
| (ii) Related organizations?  |     | X  |
| b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? |     |    |
- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

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

Complete if the organization answered "Yes" 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		132,484.	132,484.	0.
d Equipment		57,100.	55,121.	1,979.
e Other		43,744.	43,291.	453.
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B))				2,432.

**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, line 12, col. (B))		

**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, line 13, col. (B))		

**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, line 15, col. (B))	

**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) OPERATING LEASE LIABILITY	102,112.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, line 25, col. (B))	102,112.

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.

<b>1</b>	Total revenue, gains, and other support per audited financial statements	<b>1</b>	2,863,585.
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
<b>a</b>	Net unrealized gains (losses) on investments	<b>2a</b>	30,855.
<b>b</b>	Donated services and use of facilities	<b>2b</b>	
<b>c</b>	Recoveries of prior year grants	<b>2c</b>	
<b>d</b>	Other (Describe in Part XIII.)	<b>2d</b>	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b>	<b>2e</b>	30,855.
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b>	<b>3</b>	2,832,730.
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b	<b>4a</b>	1,780.
<b>b</b>	Other (Describe in Part XIII.)	<b>4b</b>	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b>	<b>4c</b>	1,780.
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.)	<b>5</b>	2,834,510.

**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.

<b>1</b>	Total expenses and losses per audited financial statements	<b>1</b>	3,173,770.
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
<b>a</b>	Donated services and use of facilities	<b>2a</b>	
<b>b</b>	Prior year adjustments	<b>2b</b>	
<b>c</b>	Other losses	<b>2c</b>	
<b>d</b>	Other (Describe in Part XIII.)	<b>2d</b>	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b>	<b>2e</b>	0.
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b>	<b>3</b>	3,173,770.
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b	<b>4a</b>	1,780.
<b>b</b>	Other (Describe in Part XIII.)	<b>4b</b>	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b>	<b>4c</b>	1,780.
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.)	<b>5</b>	3,175,550.

**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 PERMANENT ENDOWMENT FUNDS ARE USED TO FUND SCHOLARSHIPS WITH PEOPLE WITH SPINA BIFIDA, FUND GRANTS TO PROMOTE THE PREVENTION AND SCIENTIFIC UNDERSTANDING 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, 2023, 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.

**SCHEDULE J  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Compensation Information**

For certain Officers, Directors, Trustees, Key Employees, and Highest  
Compensated Employees  
Complete if the organization answered "Yes" on Form 990, Part IV, line 23.  
Attach to Form 990.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2023**

Open to Public  
Inspection

Name of the organization

**SPINA BIFIDA ASSOCIATION OF AMERICA**

Employer identification number

**\*\* - \*\*\* 2181**

**Part I Questions Regarding Compensation**

	Yes	No
<b>1a</b> 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"/> Travel for companions <input type="checkbox"/> Tax indemnification and gross-up payments <input type="checkbox"/> Discretionary spending account <input type="checkbox"/> Housing allowance or residence for personal use <input type="checkbox"/> Payments for business use of personal residence <input type="checkbox"/> Health or social club dues or initiation fees <input type="checkbox"/> Personal services (such as maid, chauffeur, chef)		
<b>b</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 .....	<b>1b</b>	
<b>2</b> 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? .....	<b>2</b>	
<b>3</b> 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"/> Independent compensation consultant <input type="checkbox"/> Form 990 of other organizations <input type="checkbox"/> Written employment contract <input type="checkbox"/> Compensation survey or study <input checked="" type="checkbox"/> Approval by the board or compensation committee		
<b>4</b> 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:		
<b>a</b> Receive a severance payment or change-of-control payment? .....	<b>4a</b>	<b>X</b>
<b>b</b> Participate in or receive payment from a supplemental nonqualified retirement plan? .....	<b>4b</b>	<b>X</b>
<b>c</b> Participate in or receive payment from an equity-based compensation arrangement? .....	<b>4c</b>	<b>X</b>
If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.		
<b>Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.</b>		
<b>5</b> 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:		
<b>a</b> The organization? .....	<b>5a</b>	<b>X</b>
<b>b</b> Any related organization? .....	<b>5b</b>	<b>X</b>
If "Yes" on line 5a or 5b, describe in Part III.		
<b>6</b> 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:		
<b>a</b> The organization? .....	<b>6a</b>	<b>X</b>
<b>b</b> Any related organization? .....	<b>6b</b>	<b>X</b>
If "Yes" on line 6a or 6b, describe in Part III.		
<b>7</b> 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 .....	<b>7</b>	<b>X</b>
<b>8</b> 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 .....	<b>8</b>	<b>X</b>
<b>9</b> If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)? .....	<b>9</b>	

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

Schedule J (Form 990) 2023

**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 and/or 1099-NEC 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)	141,598.	0.	0.	0.	21,879.	163,477.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
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	(i)							
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	(i)							
	(ii)							
	(i)							
	(ii)							

**Part III Supplemental Information**

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

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**SCHEDULE O  
(Form 990)**

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 Form 990-EZ.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2023**

Open to Public  
Inspection

Name of the organization

SPINA BIFIDA ASSOCIATION OF AMERICA

Employer identification number

\*\*-\*\*\*2181

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

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 NSBPR. IN 2023  
THE WORLD CONGRESS ON SPINA BIFIDA RESEARCH AND CARE HOSTED 100 HEALTH  
AND RESEARCH INSTITUTES, FROM 18 COUNTRIES AND 35 STATES WITHIN THE  
U.S. AND THE DISTRICT OF COLUMBIA.

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:

DELEGATES ARE APPOINTED BY EACH CHAPTER. THESE DELEGATES APPROVE THE SLATE  
OF BOARD MEMBERS.

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

ANY CHANGES IN THE ASSOCIATION'S BYLAWS AND ARTICLES OF INCORPORATION ARE

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

Schedule O (Form 990) 2023

LHA 332211 11-14-23



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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 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 ISSUES 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 OF INTEREST 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) 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

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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 2021.

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 IX, LINE 11G, OTHER FEES:

CONSULTANTS:

PROGRAM SERVICE EXPENSES	661,265.
MANAGEMENT AND GENERAL EXPENSES	7,230.
FUNDRAISING EXPENSES	6,669.
TOTAL EXPENSES	675,164.
TOTAL OTHER FEES ON FORM 990, PART IX, LINE 11G, COL A	675,164.

PART XII LINE 2C  
THE ASSOCIATION HAS NOT CHANGED THE OVERSIGHT OR SELECTION PROCESS OF THE AUDIT COMMITTEE.

FORM 990, PART I, LINE 5 & PART V, LINE 2A  
THE ASSOCIATION HAS CONTRACTED WITH A PROFESSIONAL EMPLOYER

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ORGANIZATION, COADVANTAGE, TO SERVE AS THE EMPLOYER OF RECORD FOR THE  
ASSOCIATION'S EMPLOYEES. AS SUCH COADVANTAGE IS RESPONSIBLE FOR TAX  
FILINGS RELATED TO EMPLOYEES. COADVANTAGE ISSUED 15 W-2 FORMS IN 2023  
FOR THE ASSOCIATION EMPLOYEES.

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Asset No.	Description	Date Acquired	Method	Life	Conv	Line No.	Unadjusted Cost Or Basis	Bus % Excl	Section 179 Expense	* Reduction In Basis	Basis For Depreciation	Beginning Accumulated Depreciation	Current Sec 179 Expense	Current Year Deduction	Ending Accumulated Depreciation
1	LEASEHOLD IMPROVEMENTS	05/31/14	SL	10.83		16	132,484.				132,484.	132,484.		0.	132,484.
	* 990 PAGE 10 TOTAL -						132,484.				132,484.	132,484.		0.	132,484.
2	CABLE - 1600 WILSON	05/12/14	SL	5.00		16	5,410.				5,410.	5,410.		0.	5,410.
3	OFFICE FURNITURE	03/31/14	SL	5.00		16	916.				916.	916.		0.	916.
4	FURNITURE MODULAR 6 STATIONS	05/30/14	SL	5.00		16	20,032.				20,032.	20,032.		0.	20,032.
5	FURNITURE MODIFICATIONS - 1600 WILSON	06/30/14	SL	5.00		16	600.				600.	600.		0.	600.
6	CONFERENCE ROOM UPGRADE	01/02/19	SL	5.00		16	1,150.				1,150.	920.		230.	1,150.
7	CONFERENCE ROOM UPGRADE	01/24/19	SL	5.00		16	2,599.				2,599.	2,036.		563.	2,599.
8	FURNITURE MODULAR 4 STATIONS	03/15/19	SL	5.00		16	13,930.				13,930.	10,808.		3,122.	13,930.
9	FURNITURE MODULAR MODIFICATION	04/04/19	SL	5.00		16	2,663.				2,663.	1,997.		666.	2,663.
	* 990 PAGE 10 TOTAL -						47,300.				47,300.	42,719.		4,581.	47,300.
10	(D)COMPUTER - DELL LATITUDE E6430	04/29/14	SL	5.00		16	1,508.				1,508.	1,508.		0.	1,508.
11	(D)SBA-CA EQUIPMENT	10/10/14	SL	5.00		16	1,542.				1,542.	1,542.		0.	1,542.
12	(D)DELL LATITUDE E5440	02/26/15	SL	5.00		16	1,578.				1,578.	1,578.		0.	1,578.
13	(D)DELL E5550/24'' LED MONITOR	07/31/15	SL	5.00		16	1,609.				1,609.	1,609.		0.	1,609.
16	(D)COMPUTER - DELL LATITUDE 5580 BTX	12/18/17	SL	5.00		16	1,545.				1,545.	1,545.		0.	1,545.
17	(D)COMPUTER - DELL LATITUDE 5580 BTX	04/12/18	SL	5.00		16	1,448.				1,448.	1,448.		0.	1,448.
21	COMPUTER - DELL LATITUDE 5590	03/09/19	SL	3.00		16	1,424.				1,424.	1,424.		0.	1,424.

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(D) - Asset disposed

\* ITC, Salvage, Bonus, Commercial Revitalization Deduction, GO Zone

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Asset No.	Description	Date Acquired	Method	Life	Conv	Line No.	Unadjusted Cost Or Basis	Bus % Excl	Section 179 Expense	* Reduction In Basis	Basis For Depreciation	Beginning Accumulated Depreciation	Current Sec 179 Expense	Current Year Deduction	Ending Accumulated Depreciation
22	COMPUTER - DELL LATITUDE 5590	03/09/19	SL	3.00		16	733.				733.	733.		0.	733.
23	(D)COMPUTER - DELL LATITUDE 5591	05/20/19	SL	3.00		16	1,487.				1,487.	1,487.		0.	1,487.
24	(D)COMPUTER - DELL XPS I7	02/03/20	SL	3.00		16	2,140.				2,140.	2,140.		0.	2,140.
25	COMPUTER - DELL XPS 13	08/27/21	SL	3.00		16	1,707.				1,707.	1,707.		0.	1,707.
26	COMPUTER - HP ENVY	03/02/22	SL	3.00		16	725.				725.	725.		0.	725.
27	COMPUTER - LENOVO IDEAPAD	03/08/22	SL	3.00		16	616.				616.	616.		0.	616.
28	COMPUTER - 2022 HP	05/03/22	SL	3.00		16	540.				540.	540.		0.	540.
29	COMPUTER - HP FHD	08/18/22	SL	3.00		16	500.				500.	500.		0.	500.
30	SP OWL CONFERNCE MODULE	08/28/22	SL	3.00		16	1,471.				1,471.	1,471.		0.	1,471.
34	(D)DELL LATITUDE E5520	04/30/17	SL	5.00		16	1,627.				1,627.	1,627.		0.	1,627.
35	(D)EQUIPMENT - PHONE SYSTEM (1502)	02/28/16	SL	5.00		16	1,613.				1,613.	1,613.		0.	1,613.
36	(D)EQUIPMENT - PHONE SYSTEM (1502)	02/28/16	SL	5.00		16	1,613.				1,613.	1,613.		0.	1,613.
37	(D)SERVER UP-GRADE RACK & SWITCH (1502)	09/30/16	SL	5.00		16	10,886.				10,886.	10,886.		0.	10,886.
38	DELL XPS 15	11/27/23	SL	3.00		16	2,083.				2,083.			58.	58.
	* 990 PAGE 10 TOTAL -						38,395.				38,395.	36,312.		58.	36,370.
32	MIP SOFTWARE - UPGRADE	03/14/19	SL	5.00		16	13,600.				13,600.	10,427.		2,720.	13,147.
33	OTHER SOFTWARE	04/29/14	SL	3.00		16	30,144.				30,144.	30,144.		0.	30,144.
	* 990 PAGE 10 TOTAL -						43,744.				43,744.	40,571.		2,720.	43,291.

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(D) - Asset disposed

\* ITC, Salvage, Bonus, Commercial Revitalization Deduction, GO Zone

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Asset No.	Description	Date Acquired	Method	Life	Conv	Line No.	Unadjusted Cost Or Basis	Bus % Excl	Section 179 Expense	* Reduction In Basis	Basis For Depreciation	Beginning Accumulated Depreciation	Current Sec 179 Expense	Current Year Deduction	Ending Accumulated Depreciation
	* GRAND TOTAL 990 PAGE 10 DEPR						261,923.				261,923.	252,086.		7,359.	259,445.
	CURRENT YEAR ACTIVITY														
	BEGINNING BALANCE						259,840.			0.	259,840.	252,086.			259,387.
	ACQUISITIONS						2,083.			0.	2,083.	0.			58.
	DISPOSITIONS/RETIRED						28,596.			0.	28,596.	28,596.			28,596.
	ENDING BALANCE						233,327.			0.	233,327.	223,490.			230,849.
	ENDING ACCUM DEPR LESS DISPOSITIONS											230,849.			
	ENDING BOOK VALUE											2,478.			